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Willingness to adopt digital behavior change interventions in people with chronic conditions

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Abstract in English

Title: Willingness to adopt digital behavior change interventions in people with chronic conditions

Abstract: Digital behavior change interventions can help fulfill the unmet need for timely, personalized behavior-change support for patients with chronic conditions. However, many components of digital behavior change interventions, such as enacting continuous monitoring and receiving frequent feedback, can become intrusive to patients' lives. How patients might weigh this impact against the promised benefits of digital behavior change interventions, to decide whether they are willing to adopt them or not, is unknown. In this thesis, we sought to identify the intervention components and patient characteristics that contribute to patients' perception of digital behavior change interventions as intrusive, and assess how intrusiveness relates to patients' willingness to adopt digital behavior change interventions in their usual care. In our first project, we conducted a vignette study with 1010 patients with type 1 and type 2 diabetes from 30 countries. We assessed the perceived intrusiveness of digital behavior change interventions composed of different modalities. We collected qualitative data regarding why patients considered specific modalities as intrusive. Our study focused on monitoring and feedback, two of the most commonly used behavior-change techniques. We identified a positive, significant association between intrusiveness and: the addition of food monitoring, compared with glucose- and PA-monitoring alone, permanent monitoring with real-time physician-generated feedback, compared with monitoring for a week with feedback in consultation, and private-sector data handling compared with public-sector data handling. The qualitative analysis identified 4 drivers of intrusiveness: burden, control, data safety/misuse, and dehumanization of care. We subsequently analyzed the data collected in the first study to assess the relationship between intervention characteristics, intrusiveness and patients' willingness to adopt digital behavior change interventions. Specifically, we sought to identify the minimum effectiveness at improving different health outcomes, for which patients would adopt digital behavior change

interventions with varying degrees of intrusiveness. We found that patients require greater minimum effectiveness to adopt interventions perceived to be more intrusive. Our third project was motivated by the shift towards digital care imposed by the COVID-19 pandemic. In a mixed-methods survey with 1599 patients with chronic conditions, we quantified patients' ideal post-pandemic balance of digital and traditional care, and identified the appropriate circumstances in which digital care modalities could replace traditional care modalities, according to patients. We found that patients would be willing to replace traditional care with digital care modalities for 22 to 52% of their future needs, and we identified 67 care activities, patient characteristics, and characteristics of digital care modalities, for which patients considered it appropriate to replace traditional with digital care. We discuss how our findings inform the post-pandemic integration of digital behavior change interventions in patients' care. This work helps us to understand how we can reduce the intrusiveness of digital behavior change interventions, to ensure patients are capable and willing to adopt them. The next steps in this line of work are to measure patients' experience of using digital behavior change interventions longitudinally, including perceived intrusiveness and treatment burden, and to develop shared decision-making aids for digital health and behavior change interventions.

Keywords: digital health; behavior change; chronic conditions; acceptability; intrusiveness

Résumé court en français

Titre : Acceptabilité des interventions numériques visant à modifier le comportement des individus atteints de maladies chroniques

Les interventions numériques comportementales (INC) utilisent des dispositifs numériques, afin d'aider les patients à modifier leur mode de vie. Grâce aux algorithmes, les INC peuvent être automatisées et personnalisées, afin d'offrir des moyens adaptés aux besoins de chaque patient (par exemple des techniques de changement de comportement). Ces interventions sont particulièrement pertinentes pour les patients atteints de maladies chroniques, qui sont souvent amenés à modifier leur mode de vie afin de gérer les symptômes de leur maladie. Cependant, les INC peuvent se révéler intrusives pour la vie privée. Dans cette optique, l'intrusion des INC dans la vie privée représente un coût que le patient doit assumer pour obtenir ses bienfaits. Le premier objectif de cette thèse était d'identifier les caractéristiques des INC ainsi que les caractéristiques des patients pouvant impacter le niveau perçu d'intrusion des INC par les patients. Le deuxième objectif, était d'identifier comment le niveau d'intrusion, ainsi que les caractéristiques des INC, sont liés à la volonté des patients d'adopter les INC dans le cadre de leurs soins courants. Nous avons mené une enquête internationale à méthodes mixtes, basée sur des vignettes, auprès de 1010 patients de 30 pays différents, ayant un diabète de type 1 ou 2. Les participants ont évalué des vignettes décrivant différents types d'INC, composés de différents dispositifs de surveillance, ainsi que les différentes modalités d'intervention médicamenteuse et comportementale sur la base des données captées. Pour chaque vignette, les participants ont évalué le niveau d'intrusion d'INC, et le bénéfice minimal pour lequel ils seraient prêts à l'adopter pour leurs propres soins. Les participants ont également répondu à deux questions ouvertes, décrivant ce qu'ils trouvaient intrusif dans les vignettes. Nous avons analysé les données quantitatives en utilisant des modèles mixtes afin d'identifier les dispositifs de surveillance et les modalités d'intervention qui sont associés à un niveau d'intrusion élevé, et afin d'identifier le bénéfice minimal requis par les patients pour adopter des INC ayant différents niveaux d'intrusion. L'analyse

qualitative a permis d'identifier 4 thèmes expliquant pourquoi les INC peuvent être considérées comme intrusives. Notre troisième étude a été motivée par l'augmentation d'utilisation des soins connectés pendant la pandémie de la COVID-19. Nous avons mené une enquête à méthode mixte auprès de 1529 adultes atteints de maladies chroniques, afin de quantifier l'équilibre idéal entre les soins numériques et les soins en présentiel, et d'identifier les circonstances dans lesquelles les soins numériques pourraient remplacer les soins en présentiel selon les patients. Dans le contexte de cette thèse, les résultats de cette étude peuvent éclairer sur l'intégration potentielle des INC dans les soins après la pandémie. Au total, les résultats de cette thèse montrent que le niveau d'intrusion et le bénéfice requis pour adopter la même INC peuvent varier de manière importante d'un patient à l'autre. Les médecins qui souhaitent utiliser les INC pour le traitement de leurs patients doivent prendre en compte l'hétérogénéité de l'acceptabilité des INC en utilisant les aides à la prise de décision partagée. Des solutions devront être identifiées afin de rendre les INC moins intrusives au niveau du développement des capteurs et des logiciels sur lesquels ces interventions sont basées.

Mots clefs : santé connectée ; numérique ; mode de vie; comportements de santé ; maladies chroniques ; acceptabilité ; intrusion

Résumé substantiel en français

Les interventions visant à modifier les comportements de santé pourraient réduire le taux de mortalité et les dépenses de santé en agissant sur le mode de vie. Les dispositifs numériques (ex : les capteurs, les applications pour smartphone), peuvent être utilisés afin de proposer des interventions comportementales à un plus grand nombre d'individus et à un coût plus faible comparativement aux interventions en présentiel (ex : consultations avec un psychologue spécialiste du sevrage tabagique). Les interventions numériques et comportementales (INC) peuvent être automatisées et personnalisées, afin d'offrir des éléments adaptés aux besoins et aux capacités de l'individu, comme des techniques de changement de comportement.

Les INC sont particulièrement pertinentes pour les patients atteints de maladies chroniques. 40% des adultes aux États-Unis ont au moins une maladie chronique. Ces patients sont souvent amenés à modifier leur comportement, afin de gérer les symptômes de leur maladie ou de prévenir l'apparition d'autres maladies chroniques. Malgré son importance, les patients atteints de maladies chroniques ont rarement accès à un soutien adéquat dans le cadre de leurs soins pour aider à modifier leur mode de vie.

Les INC pour les patients atteints de maladies chroniques peuvent prendre différentes formes. Par exemple, un patient atteint de diabète de type 2 peut surveiller sa consommation alimentaire à l'aide d'une application pour smartphone et partager un résumé des données de l'application avec son médecin lors des consultations de suivi. Ceci peut se faire en conjonction avec d'autres données, comme le dosage de l'HbA1c. Un patient atteint d'asthme peut utiliser une application pour smartphone conçue pour l'aide au sevrage tabagique, avec une surveillance pluri quotidienne des facteurs pouvant l'inciter de fumer (comme son niveau de stress). Sur la base de ces données, un algorithme estime en temps réel son risque de fumer dans les prochaines heures. Cela permet à

l'application d'afficher des messages personnalisés afin d'aider le patient à éviter une rechute, au moment où il est à un risque élevé.

L'utilisation d'INC par les patients soulève des problèmes différents de ceux rencontrés par les utilisateurs non malades. D'abord, les INC peuvent être prescrites aux patients par leur médecin dans le cadre de leur traitement existant. Cela implique que, contrairement aux personnes non malades, les patients n'ont pas la liberté de choisir l'intervention selon leur préférence. Dans certains cas où le comportement désiré doit être pérennisé (par exemple, l'adhésion thérapeutique), les patients doivent utiliser l'INC tout au long de leur vie. De plus, les INC transforment le domicile ou le lieu de travail en un lieu où la maladie chronique doit être observée et soignée, comme à l'hôpital ou au cabinet du médecin. Enfin, en donnant à son médecin l'accès aux données sur son comportement et sa fonction physique, le patient risque également de perdre son autonomie dans la gestion de sa maladie.

Ces phénomènes sont décrits par les sociologues comme une intrusion de la santé numérique dans la vie privée du patient. Dans cette optique, l'intrusion des INC dans la vie privée représente un coût que le patient doit payer pour obtenir les éventuels bienfaits des INC sur sa santé et sa qualité de vie. En effet, afin de décider d'adopter une INC, le patient doit mettre en balance ces bénéfices et ces coûts psychologiques et pratiques. Notamment les INC personnalisées représentent un équilibre cout-bénéfice intéressant : plus l'INC obtient de données sur son utilisateur, en le surveillant dans sa vie quotidienne, plus elle peut sélectionner le traitement précis dont l'utilisateur a besoin, devenant ainsi plus efficace. Cependant, le niveau de surveillance nécessaire pour collecter ces données, peut rendre les INC personnalisés plus intrusives, ce qui peut, à son tour, avoir un impact sur la volonté des patients à l'utiliser.

Le premier objectif de cette thèse, était d'identifier les caractéristiques des INC et des patients pouvant avoir un impact sur le niveau perçu d'intrusion des INC par les patients. Le deuxième objectif était d'identifier comment le niveau d'intrusion, ainsi que les caractéristiques des INC et des patients, sont liées à la volonté des patients d'adopter les INC dans le cadre de leurs soins.

Les données de la littérature sur l'intrusion INC concernent principalement l'utilisation des outils de surveillance, tels que la balance connectée ou le tensiomètre connecté. Des études observationnelles montrent que certains patients considèrent ces appareils comme une intrusion dans leur lieu de vie ainsi que dans leurs relations sociales, et que l'intrusion perçue peut avoir un impact sur la volonté des patients à utiliser ces appareils. Par exemple, certains patients refusent d'utiliser des dispositifs numériques disposant d'alertes sonores, pouvant attirer l'attention dans les lieux publiques en dehors du domicile, même si l'utilisation d'appareil en continu leur est conseillé. Cependant, les données de la littérature reposent sur des études ayant de petits échantillons, dans lesquelles tous les participants utilisent un seul appareil de surveillance numérique. A notre connaissance, il n'existe aucune étude comparant le niveau d'intrusion entre différents outils de surveillance ou différentes modalités de partage des données de surveillance avec les soignants. Si l'utilisation des INC est effectivement perçue comme intrusive pour la vie privée, son impact éventuel sur la vie des patients et sur leur volonté d'adopter ou non les INC doit être mesuré, et des solutions visant à réduire l'intrusion des INC doivent être élaborées.

Notre première étude est une enquête internationale à méthodes mixtes, basée sur des vignettes. L'étude avait deux objectifs : 1) évaluer la relation entre les différentes modalités de surveillance numérique et de feedback par les soignants sur les données captées, et le niveau perçu d'intrusion, et 2) obtenir une description qualitative de ce que les patients considèrent comme intrusif dans les INC. Nous avons choisi de cibler cette étude sur les INC utilisées par les patients atteints de diabète type 1 ou type 2. Cette population a été sélectionnée en raison de l'utilisation répandue des dispositifs numériques pour la gestion du diabète, et parce que les patients diabétiques sont souvent amenés à changer leur comportement/mode de vie, notamment en matière de la nutrition et de l'activité physique.

Nous avons utilisé des vignettes, c'est-à-dire des scenarios courts décrivant différents types de soins, dans le but de présenter les différents dispositifs de surveillance (différents outils de surveillance

numérique pour mesurer l'activité physique, l'alimentation et la glycémie), ainsi que les différentes modalités d'intervention médicamenteuse et comportementale sur la base des données captées (comme par exemple, des conseils personnalisés de changement de comportement pour améliorer le régime alimentaire fournis par une application sur smartphone ou par un soignant par consultation téléphonique). Les participants ont évalué le niveau d'intrusion perçu pour chaque vignette, sur une échelle de 1 à 5. Les participants ont également répondu à des questions ouvertes, décrivant ce qu'ils trouvaient intrusif dans les vignettes.

1010 participants issus de 30 pays ont évalué 2860 vignettes. Les vignettes étaient évaluées comme plus intrusives lorsqu'elles comprenaient l'ajout d'une surveillance de l'alimentation, occasionnelle ou régulière (à la surveillance glycémique et de l'activité physique), et l'intervention, en temps réel, par le médecin référent ou un autre soignant (comparé à l'utilisation d'INC à court terme avant une consultation avec une intervention en consultation). L'analyse qualitative a permis d'identifier 41 raisons pour lesquelles l'INC était considérée comme intrusive, regroupées en 4 grands thèmes : le fardeau pratique et psychologique de l'INC (par exemple, la stigmatisation liée à l'utilisation d'outils de surveillance en public), la perte d'autonomie (par exemple, certains participants avaient peur de perdre le contrôle de leur maladie à cause de la surveillance en continue par leur médecin), les risques autour de la confidentialité des données captées, et la déshumanisation des soins.

Après avoir identifié la relation entre des caractéristiques des INC et l'intrusion, nous avons exploré la relation entre le niveau d'intrusion des INC et leur acceptabilité. Des études qualitatives montrent que certains patients refusent l'adoption de dispositifs de surveillance de santé à cause de leur caractère intrusif. Dans ce cadre, l'intrusion représente un coût psychologique indissociable du potentiel effet bénéfique des INC. En effet, des études montrent que l'observance des patients découle d'une évaluation de la balance des bénéfices et des risques d'un traitement, incluant l'impact du traitement sur leur vie. Si le patient considère que le risque est supérieur au bénéfice, alors il ne suivra pas son traitement. Nous avons donc formulé l'hypothèse suivante : plus le niveau perçu d'intrusion

d’une INC augmente, plus les patients exigeront un effet bénéfique important sur leur santé pour l'adopter. Du point de vue de cette estimation coûts-bénéfices, les INC représentent un cas intéressant comparé aux interventions numériques qui ne délivrent que des traitements pharmacologiques. En général, la surveillance du comportement et des interventions comportementales ne fait pas partie de la prise en charge des patients atteints de maladies chroniques. Ces interventions peuvent augmenter le fardeau de traitement du patient de façon importante, parce qu’elles exigent l’exécution de tâches pénibles (par exemple, saisir les données sur trous leurs repas dans une application de suivi nutritionnelle) qui sont souvent associées à des comportements stigmatisants (par exemple, la stigmatisation associée à la nutrition et à la prise du poids pour les patients atteints de diabète de type 2, pourrait rendre la surveillance du régime nutritionnel intrusive). En revanche, les interventions pharmacologiques numériques ont plutôt tendance à diminuer le fardeau de traitement (par exemple, l’utilisation du pancréas artificiel supprime la nécessité de mesurer sa glycémie par piqûre au doigt et de calculer la dose d'insuline correspondante, deux tâches qui sont lourdes dans le quotidien du patient, et parfois incommodes à effectuer en public).

L'objectif de notre deuxième projet était d'identifier le bénéfice minimal requis par les patients pour adopter des INC ayant différents niveaux d'intrusion. Dans cette étude, nous avons analysé les données recueillies dans l'enquête décrite ci-dessus. Dans cette enquête, 1010 participants ont évalué l'efficacité minimale à réduire la fréquence des hypoglycémies à court terme, et à prévenir les complications oculaires à long terme, pour laquelle ils adopteraient chaque INC, décrite sous forme de vignettes, sur une échelle de 1 à 5. Les participants demandaient une efficacité plus importante pour adopter les INC qu'ils évaluaient comme plus intrusives. En ce qui concerne les modalités d’INC, les participants demandaient une plus importante efficacité pour adopter des INC comprenant une surveillance supplémentaire, occasionnelle ou régulière, de l'alimentation (par rapport à la surveillance de la glycémie et de l'activité physique uniquement), et des INC comprenant une surveillance permanente avec un feedback en temps réel par un médecin ou en feedback en temps

réel généré automatiquement par un algorithme (par rapport à une utilisation à court terme avec un feedback par leur médecin en consultation).

Les résultats de ces deux études montrent que le niveau d'intrusion et le bénéfice requis pour une même INC peuvent varier de manière importante d'un patient à l'autre. Les médecins qui souhaitent utiliser les INC dans la prise en charge de leurs patients doivent donc prendre en compte l'hétérogénéité de cette acceptabilité. En utilisant des aides à la prise de décision partagée, les médecins pourraient mieux comprendre comment leurs patients souhaitent intégrer l'INC dans leur vie quotidienne, quelles sont leurs attentes en termes de bénéfice de l'INC, et ainsi d'identifier l'INC qui correspond le mieux à chaque patient. En outre, le lien entre l'intrusion et le bénéfice requis pour l'adoption des INC souligne l'importance d'identifier des pistes afin de les rendre moins intrusives. Les résultats de notre première étude suggèrent deux solutions. La première solution serait l'amélioration du développement des outils connectés (par exemple, favoriser la création des capteurs discrets, qui peuvent être portés sur des parties du corps moins voyants). La deuxième solution nécessiterait l'amélioration de la relation médecin-patient afin de diminuer la peur de la perte d'autonomie dans la gestion de leur santé et du risque de reproches sur leurs habitudes alimentaires

Notre troisième étude a été motivée par l'augmentation de l'utilisation du numérique dans la santé pendant la crise sanitaire COVID-19. En effet, en 2020 et 2021 un grand nombre de patients atteints de maladies chroniques ont utilisé des modalités de soins connectés ou à distance. Certains médecins et organisations de soins aimeraient continuer à proposer ces modalités de soins même après la pandémie. A ce jour, aucune étude n'a évalué quel serait l'équilibre idéal entre soins en présentiel et soins connectés/à distance selon les patients, après la fin de la pandémie. Nous avons mené une enquête à méthode mixte auprès de 1529 adultes atteints de maladies chroniques, membres de la communauté ComPaRe (https://compare.aphp.fr/), et recrutés entre janvier et février 2021. Nos objectifs étaient : 1) de quantifier l'équilibre idéal entre les soins numériques et les soins en présentiel, et 2) d'identifier les circonstances dans lesquelles les soins numériques pourraient remplacer les soins

en présentiel selon les patients. Plus précisément, nous nous sommes concentrés sur trois modalités de soins : téléconsultations versus consultations en présentiel, utilisation d'un symptôme-checker (un questionnaire en ligne interactif, qui propose la bonne marche à suivre selon les symptômes signalés par les patients) versus prise de contact avec son médecin quand le patient fait face aux nouveaux symptômes, et surveillance du patient à distance afin d'adapter son traitement hors consultation versus partage des données de surveillance en consultation présentielle.

Trois résultats de cette étude sont particulièrement pertinents pour l'acceptabilité des INC. D'abord, nous avons identifié 67 circonstances dans lesquelles les soins numériques pourraient remplacer les soins en présentiel. Les patients favorisent l'utilisation du numérique dans des circonstances " à faible risque ", où le bénéfice obtenu par les soins en présentiel ne justifie pas l'effort dépensé par les patients (par exemple, temps de trajet pour s'y rendre au lieu de consultation). Étant donné que les interventions visant à changer les comportements de santé représente un soin à faible risque, il est probable que les patients favorisaient le développement d'INC à distance dans ce cadre. Deuxièmement, dans les 67 circonstances appropriées pour l'utilisation des soins numériques sont inclus les caractéristiques du patient et les caractéristiques de soins dont il souhaite bénéficier. Par exemple, les soins numériques ont été considérés comme appropriés pour les patients dont la maladie était stable, et qui avaient une relation de confiance établie avec leur médecin. Ces informations subjectives et nuancées, qui peuvent changer au fil du temps, ne peuvent être obtenues que par une discussion entre le patient et le médecin, sur la base des principes de la prise de décision partagée. Enfin, les participants ont exprimé le souhait de poursuivre l'intégration d'INC utilisées pendant la pandémie en prise en charge post pandémique, comme les cours de sport en ligne, ou des applications de rappel de prise de médicaments sur smartphone. Cependant, ces INC étaient déjà disponibles avant la pandémie, et probablement connues des patients. Ces résultats soulignent plutôt une demande de structuration et de personnalisation de l'offre de soins des INC de la part des patients . A titre d'exemple, une participante atteinte d'endométriose a proposé la création de cours de sport en ligne

en temps réel adapté au soulagement des symptômes de l'endométriose et d'en limiter l'accès aux patientes souffrant de la même pathologie.

Les résultats de cette thèse pourraient aider les soignants à identifier et recommander des INC jugés acceptables par les patients. En effet, nous avons constaté que les patients ont des opinions tranchées sur les INC avec un risque de rejet des interventions ne correspondant pas à leurs besoins, capacités et préférences. Par conséquent, la méthode actuelle de mise en place d'interventions visant à modifier le mode de vie des patients (c'est-à-dire, proposer qu'une seule intervention, sans alternatif et sans possibilité de modifier des modalités d'intervention, comme par exemple sa fréquence), ne nous semble pas adaptée dans le cadre d'un système de soins centré sur le patient. Les patients pourraient bénéficier d'une approche plus souple, comme un système de sélection des interventions visant à modifier le comportement « à la carte », où les patients pourraient choisir parmi diverses techniques de changement du comportement (surveiller son comportement, fixer d'objectifs, recevoir du feedback ou du contenu éducatif, etc.) et diverses modalités (en présentiel ou à distance, fréquence et durée de l'intervention) selon leurs besoins et préférences.

Sur la base de nos résultats, nous recommandons que les recherches futures examinent le lien entre l'intrusion et l'adoption des INC de façon longitudinale, nos résultats étant basés sur les données de préférence déclarée des patients recueillis par de questionnaires en ligne (c'est-à-dire excluant les patients qui n'ont pas accès à Internet). L'impact de l'utilisation des INC sur le fardeau du traitement devrait également être examiné. Nos résultats montrent que des interventions numériques pourraient réduire certains aspects du fardeau du traitement (associés à l'exécution de tâches quotidiens, comme l'autosurveillance de la glycémie), mais en exacerber d'autres (associés à la disruption de la vie sociale et professionnelle du patient). Sur le plan méthodologique, nous soulignons l'importance de la collaboration des patients pour le développement de futures études de recherche. Dans le cadre de cette thèse, des patients ont contribué au développement des questionnaires, notamment via leur participation à des entretiens cognitifs (par exemple, certaines questions ouvertes inclues dans les

questionnaires ont été rédigées suite aux propositions de patients au cours de l'entretien). Le développement d'aides à la prise de décision partagée, afin d'aider les médecins et les patients à sélectionner l'INC la plus adaptée à leurs besoins, pourrait également être envisagé. L'utilisation de la prise de décision partagée dans le domaine des soins numériques deviendra particulièrement pertinente avec l'augmentation du nombre d'INC disponibles (par exemple, à mesure que de multiples applications efficaces pour le sevrage tabagique deviennent disponibles). En outre, il est important que de continuer à faire valider par les cliniciens la volonté des patients de poursuivre l'utilisation d'INC dans le cadre où les facteurs pouvant impacter leur utilisation évoluent au cours du temps, notamment en fonction de l'état de santé du patient.

Nos travaux contribuent également aux recherches sur l'automatisation des soins. L'utilisation de l'intelligence artificielle dans le cadre de l'automatisation des soins inquiète quant au risque de dégradation de la relation patient-médecin. Cependant, certains patients souffrent déjà d'un manque de confiance envers leurs médecins dans le système de soins en place. Dans ce contexte, la communication autour de comportements stigmatisés, comme l'alimentation, devient un véritable défi. Les interventions automatisées neutres et sans jugements, dans lesquelles les humains n'ont pas accès aux données captées et ne fournissent pas de feedback, pourraient donc être bien perçues par les patients. En parallèle, les médecins doivent contribuer au développement de relations plus égalitaires et respectueuses avec leurs patients, afin de faciliter la mise en place des INC.

En conclusion, nous proposons le développement des soins comportementaux fondés sur une prise de décision partagée, dans lesquels chaque patient pourrait recevoir l'INC composée des modalités qui lui conviennent en fonction de ses valeurs, de son mode de vie et de sa capacité à supporter les coûts psychologiques et pratiques associés à l'INC. Pour cela, il faudrait accorder plus d'autonomie aux patients, et appliquer les principes de *minimally disruptive medicine* aux soins numériques et aux soins comportementaux..

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List of abbreviations

AI, Artificial intelligence

BCT, Behavior change technique

CI, Confidence interval

COVID-19, Coronavirus disease (SARS-CoV-2)

DBCI, Digital behavior change intervention

IQR, Interquartile range

RCT, Randomized controlled trial

RDM, Remote digital monitoring

RR, Risk ratio

SD, Standard deviation

Introduction

Health behavior change interventions

The umbrella term *health behavior-change interventions* is used to indicate interventions that aim to support people in changing health-related behaviors. These interventions vary regarding the behavior they target, the level at which they are implemented (e.g., population-level campaigns versus interventions for individuals), their duration, the means of delivery, the degree of automation (e.g., delivered by a human or an algorithm), and the type of behavior-change techniques they contain (behavior-change techniques, BCTs, are the "active ingredients" of interventions, such as self-monitoring behavior, setting goals and receiving feedback).[1,2]

The benefit of effective behavior-change interventions lies in their potential ability to reduce mortality, disability and health care spending, by addressing behavioral determinants of health. These determinants include nutrition, physical activity, smoking, alcohol and substance use, sexual health behaviors and self-management behaviors for people with chronic illness (e.g., treatment adherence, self-monitoring, limiting the intake of specific nutrients, performing rehabilitation exercises). For example, tobacco smoking and physical inactivity alone are responsible for 11.7 million deaths and cost billions to health care systems worldwide.[3–5]

There are conflicting results on the effectiveness of behavior-change interventions, attributable to the heterogeneity in intervention content and delivery parameters,[6] and to methodological limitations (small sample sizes, high risk of bias).[7] However, some effective interventions for individuals exist for some health-related behaviors, such as increasing physical activity,[6–10] quitting smoking,[6,11] and achieving weight loss.[6,7,12] Some meta-analyses of comparative effectiveness studies assessing these interventions find small-to-moderate, statistically significant effects on health behaviors.[8]

Given the small to moderate size of beneficial effects, if we wish to obtain substantial change in health outcomes at population-level, cost-effective interventions may have to be delivered to large numbers of individuals, with diverse characteristics, and these interventions would have be accessible, acceptable, effective and safe.[13] However, scaling-up effective counseling-based behavior-change interventions can be challenging. Many of these interventions are resource-intensive (i.e., they require physical space, skilled personnel that are trained in following counseling protocols, travel and wait time on behalf of intervention recipients) and inaccessible to some individuals (e.g., rural area residents where few health care professionals trained in behavioral counseling may be available).[13]

Digital behavior change interventions

Digital behavior change interventions (DBCIs) are behavior change interventions that are delivered by using digital devices, such as wearable sensors and smartphone apps.[13–15] DBCIs have been proposed as a solution to bridge the above-mentioned gap between the supply and need for behavior-change interventions. First, digital technologies could support the scale-up of non-automated, remote behavior change interventions that are delivered by human professionals (e.g., by text-message, video-call or online chat). Secondly, digital technologies can be used to automate the delivery of behavior change interventions. For example, an app could be used to monitor the behavior of an individual, select the right BCT for their current needs based on a predefined algorithm, and deliver it without any human involvement in either the selection or delivery of the intervention component. The widespread use of digital technologies (71% of the French population use smartphones,[16] 83% use the internet),[17] and the increase in affordable, accurate wearable devices that monitor users' behavior and biological parameters, could enable the use of DBCIs at scale.

However, the real opportunity that DBCIs present, lies in their ability to deliver personalized support that is adapted to the individual's needs and circumstances,[1] potentially in near-real-time and across life contexts (e.g., at home, at work, in social settings), where health behavior takes place.[18] This could offer an important advantage over traditional counseling interventions, which are infrequent and take place in healthcare settings. These interventions may not be fit to address many factors that affect patients' health, because these are often transient, contextual, and occur unexpectedly (e.g., the presence of another person smoking during a work break may trigger a strong urge to smoke in the patient, who find themselves without immediate access to their smoking cessation counselor). Digital interventions, often omnipresent via the ubiquitous smartphone, have the potential to support the patient in the moment when they need support. Sophisticated DBCIs may also be able to deliver support only when the patient is receptive to it (e.g., refrain from sending text messages prompting the patient to exercise when they attend the weekly work meeting), thereby being minimally disruptive to patients' daily routines.[19,20]

The personalization capabilities of DBCIs could offer the added benefit of delivering support that accommodates different users, in addition to offering support at scale and at low cost. This additional parameter could make personalized DBCIs particularly well-suited to support behavior-change. Behavior is driven by many factors that affect an individual's motivation, capability and opportunity to enact healthy behavior.[21] Psychologists have developed 93 different BCTs that can be used to address these determinants.[19] Selecting the right BCT, for the right person, at the right time may require sophisticated personalization based on monitoring behavioral determinants and associating these with the right BCTs by using decision rules, concisely expressed in the form of algorithms.

[1] Non-personalized interventions are uniformly delivered to all users. In personalized interventions, one or more components are adapted based on the characteristics of the user and/or their environment.

DBCIs for patients with chronic conditions

In the United States, 40% of adults have at least one chronic condition, 27% have multiple conditions (i.e., multimorbidity), and the care of people with chronic conditions accounts for 90% of health care spending.[22,23]

Patients with chronic illness can greatly benefit from behavior-change interventions. Patients are often advised by their physicians to change health-related behaviors to prevent the appearance of additional chronic conditions or to manage the symptoms of the existing condition. Several meta-analyses suggest that behavior change can have beneficial effects for chronically ill adults. For example, weight loss interventions can decrease all-cause mortality in adults with obesity by 18% (risk ratio [RR] 0.82, 95% confidence interval [CI], 0.71 to 0.95),[24] and quitting smoking can reduce all-cause mortality in adults with coronary heart disease by 36% (RR, 0.64; 95% CI, 0.58-0.71).[25]

Despite the importance of healthy behaviors for chronically ill patients, the current practices used by physicians to support their patients in changing behavior are inadequate. For example, although physicians often screen for lifestyle risk factors and recommend lifestyle changes to their patients (e.g., by advising smoker patients to quit),[26] they often stop short from offering further support (e.g., prescribe nicotine replacement therapy, arrange follow-up consultations),[27,28] and recent studies show that there might be a downward trend in physicians' ordering or providing diet, exercise and tobacco counseling to chronically ill patients.[29]

DBCIs designed for chronically ill patients vary widely. In their more basic form, a patient with type 2 diabetes may keep a diary of the foods they consume using a smartphone app, and a summary of these data may be discussed with their physician in routine follow-up consultations, in conjunction with other data (e.g., HbA1c levels for the same time period). At the more sophisticated end of the spectrum, a patient with COPD may use a real-time, smartphone app-based intervention for smoking cessation, in which they log data about factors that may put them at risk for smoking (e.g., stress levels, alcohol use, interaction with other smokers) several times a day, and an algorithm estimates

real-time smoking lapse risk based on these data, in order to display tailored supportive messages on the app when the user is at risk.[30]

The delivery of DBCIs for chronically ill patients is also heterogeneous. Though they can be delivered as standalone interventions (e.g., a physician may recommend an app to support smoking cessation to a patient, without prescribing pharmacologic treatment or additional counseling, and without following-up the patient's use of the app through data-sharing), DBCIs can be delivered as part of multicomponent interventions embedded in patients' care. Depending on the degree of involvement from physicians and allied health care professionals, these multicomponent interventions may be categorized as *self-management interventions* (which include BCTs such as self-monitoring symptoms, behavior and biological data, and summarizing these data in graphs or numbers to help patients bridge the gap between the observed and the target values of the monitored variables) or *remote patient monitoring interventions* (in which symptoms, behavior and biological data are monitored in non-clinical settings, such as at home, and the data trigger personalized intervention delivery by an algorithm or a human caregiver). Indeed, integrating behavioral components in patients' care could ensure that crucial information is not lost between physicians and allied health professionals (e.g., nutritionists, counselors), and could address patients' need for holistic consultations that include prevention elements, which has been identified as a patient priority for care improvement.[31]

Systematic reviews and meta-analyses have identified that some DBCIs are effective at changing some behaviors and biological parameters that interest patients and physicians, including achieving smoking cessation,[11,32] reducing systolic and diastolic blood pressure,[33] and reducing HbA1c in patients with diabetes.[34]

Challenges in the use of DBCIs by patients with chronic conditions

The use of DBCIs by patients raises different issues than the use of DBCIs by individuals without chronic conditions. The main distinction lies in the fact that the use of digital tools by non-chronically ill individuals is often enacted by their own initiative, and is associated with autonomy and empowerment. The aim is to achieve "wellness" by gaining an in-depth understanding of the factors that affect one's health through the data collected by digital monitoring tools. On the other hand, chronically ill patients may be prescribed a DBCI in the context of their existing, structured relationship with health care. For example, a DBCI may be recommended to a patient by their physician who notices the need for smoking cessation or weight loss, and who may give feedback on the patient's use of the DBCI and behavior-change progress as part of their treatment. Thereby, the DBCI involves not only the individual, but a network of people involved in the individual's care (health care professionals, informal caregivers, insurance provider, and, in some health care systems, the employer associated with one's insurance).

Three issues that do not apply to non-chronically ill individuals may arise when chronically ill people use DBCIs. First, the patient takes the risk of losing their autonomy over the management of their health, because their care network may now gain access to detailed data about the patient's behavior and physical function. Second, the timeframe for which DBCIs need to be used may differ radically between non-chronically ill individuals and chronically ill patients, who need to maintain behavior-change that supports lifelong illness management. For example, after weight loss, obese people gain back 77% of the lost weight in less than 5 years, partly due to relapse to old dietary behaviors.[35] In this case, the formerly obese patient may need to use a DBCI for several months every few years. In fact, a recent meta-analysis that aimed to identify behavior change intervention characteristics associated with maintenance of weight loss over a long time period (>12 months) found that continued availability of the intervention to participants after the end of the trial period predicted slower weight regain.[36] The authors propose that behavior change programs should remain

available after the initial program duration, so that individuals can re-engage over time to maintain weight loss. Such life-long engagement with DBCIs can be challenging, given that adherence to DBCIs declines over time.[37,38] Third, when patients use DBCIs, health care is relocated from the clinic to the home or the workplace, due to the ubiquitous presence of digital devices that monitor the patient and deliver feedback, "blurring" the barrier between the public and the private sphere.[39] The consequences of this relocation are not known. Experimental studies point to potential problems that may arise when a patient is asked to monitor their condition. For example, a recent experimental study showed that when patients with obsessive-compulsive disorder are asked to think about their obsessive symptoms and their mood, this leads to maintenance of these symptoms for up to 24 hours later, in comparison to patients being distracted from thoughts about their symptoms.[40] Unlike healthy individuals, patients may see self-monitoring as an trigger for constant rumination about their ill health, instead of as simple data logging. This raises questions about the potential harms of active monitoring in patients with psychiatric symptoms.

Sociological work has described this relocation of health care into the private sphere as an intrusion (i.e., an unwelcomed, disturbing or interrupting presence) of the patient's space.[39,41] The concept is rooted in the fact that places are not just geographical areas, but they hold meaning for people (e.g., one's home is not just a building, but a place associated with safety and family life). When health care is relocated into the private sphere, several characteristics of DBCIs can become intrusive. For example, monitoring devices that emit sound or light make the presence of the device visible to other people, inadvertently making the chronic condition visible to others and becoming a constant reminder of the condition to the patient (for further analysis of the literature on the intrusiveness of digital health interventions, see Chapter 3).[41] This leaves patients who are interested in reaping the health benefits of using a DBCI in a difficult spot: are the promised benefits worth tolerating the intrusive presence of the DBCI in one's daily life?

This cost-benefit calculation patients have to perform captures the paradox of personalization. Unlike non-personalized DBCIs, personalized DBCIs require frequent or continuous data streams to

adapt to the individual. As these interventions are embedded in daily life, they may require monitoring-related action from the user in private spaces and moments. For example, a patient may have to use an app to log the meals they intend to eat before they sit at the table, in order to receive automated feedback on how much they should consume to stay withing their daily calorie budget.[39,42] By monitoring large amounts of data, DBCIs can deliver the precise treatment the individual needs in real-time, thereby becoming more effective than non-personalized treatments. But at the same time, monitoring can make personalized DBCIs much more intrusive and burdensome than non-personalized treatments.

To achieve optimal design of DBCIs for patients with chronic conditions, we need to identify what makes patients perceive personalized DBCIs as intrusive, regarding both DBCI components and patient characteristics, and how this relates to patients' willingness to adopt an effective DBCI. Obtaining this information can help us design and deliver DBCIs that strike a balance between costs and benefits.

Aim and objectives

The aim of this thesis project was to identify what makes patients perceive personalized DBCIs as intrusive, regarding both DBCI components and patient characteristics, and how this relates to patients' willingness to adopt DBCIs in their usual care. Ultimately, obtaining this information could help us design and deliver DBCIs that strike a balance between costs and benefits that is favorable to patients with chronic conditions.

Our first project explored the perceived intrusiveness of DBCIs composed of different modalities. We conducted an international, mixed-methods, vignette-based survey that had two objectives: 1) to assess the relationship between different digital monitoring and feedback modalities and perceived intrusiveness, and 2) to obtain a qualitative description of what patients consider intrusive about different digital monitoring and feedback modalities, and why.

Our second study expanded upon the findings of our first study. After identifying the relationship between different DBCI components and perceived intrusiveness, we studied how intrusiveness relates to patients' willingness to adopt DBCIs. Although the study of intrusiveness is in itself valuable, because it represents a change in the social contract of health care, its potential impact on patients' willingness to adopt DBCI represents a more concrete challenge. The objective of our second project was to identify the minimum effectiveness required by patients to adopt different DBCIs with varying degrees of intrusiveness. In this project, minimum required effectiveness refers to the effectiveness of the DBCI at preventing specific outcomes, in relation to patients' current care (less effective, as effective or more effective than current care). Our third study was not planned at the beginning of this thesis. Instead, it was motivated by the shift towards digital, remote care imposed by the COVID-19 pandemic. In 2020, a large number of chronically ill patients used digital care modalities, ranging from teleconsultations to online symptom-checkers. Some health care organizations will continue to offer these care modalities even after the pandemic. However, there were no studies examining patients' perceptions regarding how much of their post-pandemic care should be delivered by using digital care modalities, versus the traditional care equivalent, or in which ways digital care should be combined with traditional care. Therefore, we explored which digital care modalities patients want to incorporate into their care and how, in a mixed-methods survey with 1529 chronically ill adults. We had three objectives: quantify the ideal balance of digital and traditional care modalities, identify the appropriate circumstances in which digital care could replace traditional care according to patients, and compose a description of how chronically ill patients envision the ideal post-pandemic care. In the last part of this Thesis, we present our findings and discuss how these relate to the post-pandemic integration of DBCIs in patients' care.

Part 1: Measuring the perceived intrusiveness of DBCIs

The intrusiveness of technology-based health interventions was first discussed by Fisk in 1997.[43] Fisk suggested that there is a need to develop frameworks to study the intrusion of technology-based interventions into patients' homes, emphasized the tension between intrusiveness and the patient's need for control, and suggested that intrusiveness may impact intervention acceptability. Fisk posited that the intrusiveness of remote monitoring was determined by seven factors (the user's prior experience of using remote monitoring, the attitudes of important others, the manner in which monitoring is promoted, the physical characteristics of the equipment, the amount of control the user has over the technology, the duration and frequency of interaction with the monitoring equipment, and the magnitude of the benefits obtained from remote monitoring). However, he did not provide empirical data to support these claims.

Empirical studies of the intrusiveness of technology-based interventions are scarce. An interview study with 17 community-dwelling older people who had used an alarm service comprising fall detectors and bed occupancy sensors as part of an observational study, found that some participants reported considering the intervention devices intrusive.[44] Specifically, participants disliked being unable to contact the telemedicine call center only when they considered that they needed help. Instead, the device made the "decision" to alert the call center based on the patients' data. This was experienced as loss of autonomy and control. Some participants identified intrusiveness as the reason why they did not adhere to the prescribed device use. A survey with 213 older adults that used home monitoring technologies measured intrusiveness with two questions ("This technology is intrusive", and "Through this technology, I feel that I am observed"), in addition to the constructs of trust in health technologies, social presence in health technologies (i.e., the extent at which technology makes the user feel connected to other humans), usefulness and usability. The

study found that users' level of trust in health technologies significantly impacted perceived intrusiveness, and that the perception of social presence in the use of these technologies were negatively associated with perceived intrusiveness, implying that trusted monitoring tools that make the user feel connected to others may feel less intrusive.[45] The study did not provide data as to which functions of the technology the participants found intrusive.

In an interview-based study with 95 Dutch patients with heart failure who used a home monitoring system comprised of multiple devices (connected scale, blood pressure meter, data transmission device), Oudshoorn describes a triple intrusion of the home monitoring intervention: intrusion into patients' homes, social relationships, and daily routines.[39] For example, Oudshoorn describes that both the scale and the transmission device would emit sound alerts. These alerts were noticed by others (e.g., family members) who, in turn, tried to interact with the monitoring devices. The devices reconfigured social relationships in multiple ways. For example, the patient's partner often took the position of co-inspector of their partner's health, by asking their partner if they recorded their daily measurements, examining how high the readings were, using recipes for healthier meals to contribute to reducing their partner's blood pressure or providing psychological support when the patient was discouraged because of an abnormal measurement result. The devices also disrupted patients' routines which had to be modified to accommodate daily data collection (e.g., measuring weight and blood pressure in the morning). Other patients reported that the technology transformed home from a place of freedom to a place of behavioral compliance, where they were obliged to answer phone calls from nurses that were alerted automatically when the device detected deviant measurements. The patient was obliged to be available to medical staff at all times, and they controlled neither when they took their measurements nor when they interacted with the telemedical centre. To understand how intrusiveness may manifest in monitoring devices that are used outside the home, Oudshoorn conducted additional interviews with 5 patients who used a wearable ECG recorder as part of a trial.[39] The device had to be worn continuously both at home and in public, and it emitted a sharp audio alert when it stored an ECG recording. Because the audio alert attracted

strangers' attention, patients were reluctant to use the device outdoors. The alert made their chronic condition publicly visible, blurring the boundaries between public and private life.

Finally, some studies of patients' perceptions of DBCIs that monitor exclusively behavioral (instead of biological plus behavioral) variables, provide data that point to the presence of intrusiveness. For example, in a pre-post study of the effects of a smartphone app in which participants had to use voice recognition features to record their food intake, 35% of participants reported they felt "ashamed" to use this feature in the presence of others.[46]

Taken together, these studies show that monitoring one's data, which is one of the most common BCTs used in DBCIs and the cornerstone of personalization, can be seen as intrusive by patients. Although the above-mentioned research has set the foundations for the study of intrusiveness in technology-based interventions, there are several shortcomings that should be noted. First, much of the limited literature on intrusiveness seems to focus on older adults. This is attributable to older people's need for home monitoring systems that may be perceived as invoking their autonomy and emphasizing the loss of physical and cognitive capacities necessary for independent living. However, monitoring systems have been developed for many chronic conditions, such as hypertension and type 1 diabetes, in which the intended users are, at average, younger and familiar with technology.[47,48] These patients may face different situations compared to older adults, which lead to different perceptions of intrusiveness (e.g., younger patients may have an active social and professional life outside the home, where monitoring could also take place). In addition, these studies explored the intrusiveness of either a single digital intervention, used by all participants, or, in the case of Etemad-Sajadi et al, studied a group of participants that used each a different intervention with different characteristics. Therefore, these studies provide no information about the comparative intrusiveness of different monitoring modalities (e.g., different digital monitoring tools, monitoring different behavioral variables, monitoring behavioral versus biological variables, receiving feedback by different care professionals).

If digital monitoring is indeed perceived as intrusive into patients' private, social and family lives, then its impact on patients' lives and willingness to adopt DBCIs should be measured, so that ways to reduce intrusiveness can be implemented in the design of DBCIs. Furthermore, personalization should take into account which components of DBCIs are intrusive to which patients, so that the right DBCI can be prescribed to the right patient.

Our first study had two objectives: 1) to assess the relationship between different digital monitoring modalities and perceptions of intrusiveness, and 2) to elicit patients' own description of what makes digital monitoring intrusive, by using open-ended questions. Patients with diabetes (type 1 or type 2) were selected as the sample for this study because of the widespread use of digital health technologies for diabetes management, to deliver both pharmacologic and behavior change interventions, and because behavior change is often required of this population.

We framed the different biological and behavioral monitoring, and pharmacologic and behavioral intervention components, as complete remote digital monitoring (RDM) treatment scenarios. As mentioned above, RDM refers to the use of digital sensors and devices to monitor a patient's physiological and/or behavioral data, combined with an artificial-intelligence (AI) algorithm that uses the monitoring data to identify when an intervention should be delivered to this patient. The algorithm can further personalize the intervention by identifying the right component and/or dosage for the patient. These intervention components can then be delivered by an automated device (e.g., personalized behavior-change advice to improve diet delivered by an app), or by a human that has been alerted to deliver the intervention by the algorithm.[49] In short, RDM can deliver personalized DBCIs integrated in the patient's care.

Our survey used vignettes to elicit patients' views of intrusiveness. In vignette surveys, participants are shown short scenarios (vignettes) describing different care situations, and are asked to report their views and preferences about each scenario. Vignettes are a robust study design for eliciting perceptions and stated preferences, and the stated preferences elicited with vignettes have been validated against real-world behavior.[50] In our study, vignettes described different types of

RDM. To create our vignettes, we systematically combined different options (levels) of three key RDM components in a factorial design: 1) the digital monitoring tools patients would use (3 levels), 2) the duration of use and way of receiving feedback on their data, as an intervention (6 levels), and 3) different ways of data handling (2 levels). By combining these options, we obtained 36 different vignettes. For each vignette, participants assessed the perceived intrusiveness on a 5-point scale. Participants also responded to open-ended questions, describing what they found intrusive about the vignettes and why.

We collected 2860 vignette-assessments by 1010 participants from 30 countries. We found that participants perceived RDM as more intrusive when it included the addition of occasional or regular food monitoring, as compared with glucose and physical-activity monitoring alone, permanent use with real-time feedback intervention by one's regular physician or by another care professional, as compared with short-term use before a consultation when a complication arose with feedback intervention in consultation, and as less intrusive when it included public-sector data handling (such as by a public hospital or university, as opposed to by a private insurance company) compared to private-sector data handling. Qualitative analysis identified 41 distinct codes describing why RDM was considered intrusive, clustered in 4 greater themes: practical and psychosocial burden (reported by n=468, encompassing aspects of physical obtrusiveness, the time-consuming nature of active monitoring, and concerns about stigma), control (n=440, concerning participants' fear of losing control over their health through surveillance and receipt of unsolicited feedback, and fear of monitoring data revealing unhealthy behaviors to health care professionals, attracting criticism), data privacy and misuse (n=206), and dehumanization of care (n=34).

The findings of this study point to two steps we can take to reduce intrusiveness in DBCIs. On one hand, some of the factors identified in the qualitative analysis as relevant to intrusiveness might be addressed through better design of digital monitoring tools. For example, creating sensors that can be worn on body parts that are not visible to the public, may help reduce patients' concerns of being "exposed" as chronically ill to others. Similarly, audio or visual alerts could be replaced by discrete

vibration alerts. In this view, some of the devices that have been developed to monitor behavior such as smartwatches, which have been widely adopted by the public and do not stand out, seem less intrusive than others, such as smart forks (i.e., forks that vibrate when the user eats too fast, to teach the user to eat slowly, a behavior that has been associated with weight loss),[51] which are visibly different to regular forks and thereby set the user apart from other individuals. On the other hand, we identified several factors associated with intrusiveness that seem to occur due to the nature of the patient-physician relationship. For example, patients expressed fear of being judged or criticized about their nutrition if they were to give their doctor access to their monitoring data, and concerns about being controlled and losing their freedom to manage their own treatment. These issues are rooted to the power asymmetry in the patient-physician relationship. To overcome them, it is necessary to first foster trusting patient-physician relationships, and then implement DBCIs in this safe interpersonal context.

Secondly, though our analysis identified specific DBCI and participant characteristics associated with increased intrusiveness ratings, a large part of the variability in ratings was not attributed to the variables measured in this study. The qualitative findings point to some individual characteristics that could explain the variability among participants' assessment of the same vignette, such as the need for control over one's treatment. Physicians who prescribe DBCIs should take into account the variability in patients' views.

The main limitations of this study concern the composition of the sample. Participants were recruited primarily online, and therefore had a degree of familiarity with online media and digital technologies. We also did not collect detailed information regarding participants' economic level. Although the cost of care is mitigated by universal health insurance systems for some of our participants (e.g., the French universal health insurance system already reimburses some types of digital care), economic factors can still prohibit access to digital care. For example, a patient may be unable to afford to upgrade their hardware and software (e.g., smartphone) when their digital health intervention becomes incompatible with older devices or operating systems.[52] Additionally, we did

not collect information on ethnicity or race, due to regulatory restrictions regarding the collection of ethnicity data in France.[53] Previous studies have found mixed findings regarding the association between ethnicity and digital health use.[54] These issues may limit the generalizability of our findings in populations that differ from the included participants, and prevent us from drawing conclusions on the association between socioeconomic characteristics and perceived intrusiveness.

In this study, participants were asked to rate vignettes. An alternative approach would have been to design the study as a discrete choice experiment (DCE) in which participants would be shown pairs of vignettes and asked to select the vignette that described, in their view, the more intrusive RDM. Our view at the time of study conduct was that arbitrating between two forms of RDM did not seem to fully correspond with the current reality of RDM choices. We expected patients to be offered RDM as an alternative to current care, instead of being offered multiple RDMs to select from. Therefore, in particular for the second outcome of this survey (required effectiveness to adopt RDM), we opted to ask participants to indicate required effectiveness to accept the RDM in relation to their current care. However, had we conducted the study on intrusiveness and the required effectiveness to adopt RDM separately, we might have selected a DCE for the study of intrusiveness. Though it is difficult to predict precisely how this would have altered our results, previous research comparing DCEs to vignette ratings suggested that the two methods may lead to identifying a different number of RDM factors as significant outcome predictors.[55]

Finally, the use of open-ended questions in this survey aimed to provide a better understanding of the quantitative findings. For example, findings on the awkwardness of food monitoring in public and fear around judgment by physicians upon sharing nutrition data helped clarify the association between intrusiveness and food monitoring. However, the collection of data with interviews instead of survey questions could have provided a more thorough qualitative component, which may have resulted to a more detailed understanding of intrusiveness.

The results of this study have been reported in: *Oikonomidi T, Ravaud P, James A, Cosson E, Montori V, Tran VT. An international, mixed-methods study of the perceived intrusiveness of remote digital diabetes monitoring. Mayo Clinic Proceedings 2021*. The online supplement files of the article are presented in Annex 1 of this thesis.

MAYO CLINIC

ORIGINAL ARTICLE

An International, Mixed-Methods Study of the Perceived Intrusiveness of Remote Digital Diabetes Monitoring

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Abstract

Objective: To assess the relationship between remote digital monitoring (RDM) modalities for diabetes and intrusiveness in patients' lives.

Patients and Methods: Online vignette-based survey (February 1 through July 1, 2019). Adults with diabetes (type 1, 2, or subtypes such as latent autoimmune diabetes of adulthood) assessed three randomly selected vignettes among 36 that combined different modalities for monitoring tools (three options: glucose- and physical activity [PA]−monitoring only, or glucose- and PA-monitoring with occasional or regular food monitoring), duration/feedback loops (six options: monitoring for a week before all vs before specific consultations with feedback given in consultation, vs monitoring permanently, with real-time feedback by one's physician vs by anoter caregiver, vs monitoring permanently, with real-time, artificial intelligence-generated treatment feedback vs treatment and lifestyle feedback), and data handling (two options: by the public vs private sector). We compared intrusiveness (assessed on a 5-point scale) across vignettes and used linear mixed models to identify intrusiveness determinants. We collected qualitative data to identify aspects that drove participants' perception of intrusiveness.

Results: Overall, 1010 participants from 30 countries provided 2860 vignette-assessments (52% were type 1 diabetes). The monitoring modalities associated with increased intrusiveness were food monitoring compared with glucose- and PA-monitoring alone (β=0.34; 95% CI, 0.26 to 0.42; $P<.001$) and permanent monitoring with real-time physician-generated feedback compared with monitoring for a week with feedback in consultation (β=0.25; 95% CI, 0.16 to 0.34, $P<.001$). Public-sector data handling was associated with decreased intrusiveness as compared with private-sector (β=−0.15; 95% CI, −0.22 to −0.09; $P<.001$). Four drivers of intrusiveness emerged from the qualitative analysis: practical/psychosocial burden (eg, RDM attracting attention in public), control, data safety/misuse, and dehumanization of care.

Conclusion: RDM is intrusive when it includes food monitoring, real-time human feedback, and private-sector data handling.

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Remote digital monitoring (RDM, ie, patient monitoring based on digital devices and artificial intelligence [AI]) is a novel care modality for patients with diabetes that can complement infrequent in-person consultations with continuous, real-time data streams. Remote digital monitoring is beginning to be implemented in clinical settings because of its potential benefits in achieving better health outcomes and quality of life for people with diabetes.[1-6]

Remote digital monitoring represents a paradigm shift in how diabetes care is delivered because it relocates health care from the clinic to patients' homes and transforms the role patients are expected to play in the management of their diabetes.[7,8] For example, a patient could be tasked with

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continuously monitoring glucose levels and everyday behaviors (eg, food intake) with prescribed sensors transmitting these data to their physician to receive personalized feedback for medication change or behavioral coaching, all while they are at home or at work.[9-12]

Several components in the above RDM scenario can be perceived as intrusive in patients' lives. Juggling multiple wearable devices and apps with feedback loops increases the number of tasks patients perform in their personal time and the disruptive alerts they receive. The visibility of wearable monitoring devices can attract attention in public, thereby becoming stigmatizing.[8,13] In addition to increasing treatment burden, intrusiveness can negatively affect adherence to monitoring.[8] This behavior may depend on demographic characteristics and personal attitudes.[14]

Previous studies have explored how patients perceive RDM technologies and fit them into their personal lives.[14-17] Most of these studies focused on continuous glucose monitoring (CGM) use alone (ie, without real-time feedback loops, and without behavioral monitoring)[16,18,19] and did not specifically aim to measure perceptions of intrusiveness. Therefore, their findings may not adequately inform the implementation of multivariable RDM. Studies assessing bio-behavioral monitoring with automated feedback (ie, not provided by human health care professionals but rather by AI) indicate different levels of concern regarding wearability, privacy, and usability among individual patients.[17]

To address this gap, we performed a vignette-based survey aiming to assess the relationship between different RDM modalities and perceptions of intrusiveness by patients with type 1 or 2 diabetes.

PATIENTS AND METHODS

We performed a vignette-based survey. Vignettes are hypothetical scenarios in which the presence of predefined components ("vignette factors") is varied systematically within a range of prespecified options ("factor levels"). Vignette studies have been used to elicit perceptions and stated preferences, and have been validated against real-world behavior.[20-22] Our vignettes described scenarios of RDM use for diabetes. The survey design is shown in Figure 1.

Participants

We recruited a convenience sample of adults with type 1 or 2 diabetes through social media and websites of diabetes-related associations, by email invitation to participants of the French e-cohort ComPaRe,[23] and in-person recruitment (Endocrinology Department of the Mayo Clinic, Rochester, MN), from February 1 to July 1, 2019. Recruitment was performed via different channels to avoid a highly selected sample. All participants read the information sheet, provided informed consent, and completed the survey on the study website in French or English.[24] The protocol was approved by the ethics committee of the French National Institute of Health and Medical Research (IRB 00003888).

Vignette Development

The authors (TO, VTT, and PR) selected the following RDM components (vignette factors) and modalities (factor levels) to be included in the vignettes based on a review of monitoring tools available on the market and described in the literature and by consultation with a panel of diabetologists:

1. Monitoring tools, with three modalities: 1) glucose and physical activity (PA) monitoring; 2) glucose, PA, and occasional food monitoring; or 3) glucose, PA and regular food monitoring.
2. Duration/feedback loop, with six modalities: 1) for a week, before a specific consultation, with feedback in consultation; 2) for a week, before all consultations, with feedback in consultation; 3) permanently, with real-time feedback by the patient's regular physician; 4) permanently, with real-time feedback by another care professional; or 5) permanently, with real-time, AI-generated treatment feedback; or 6) permanently, with real-time, AI-generated treatment and lifestyle feedback.

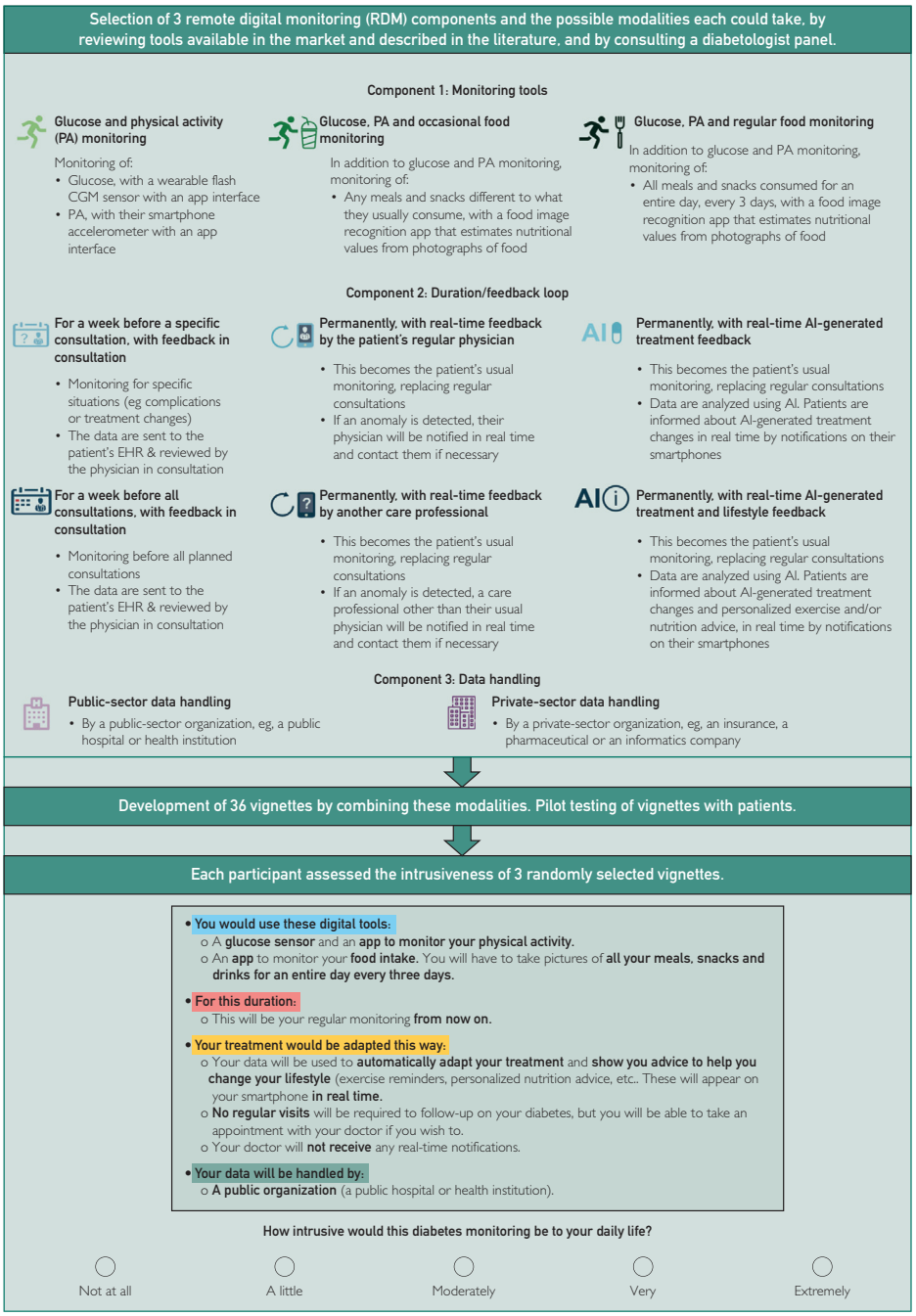

FIGURE 1. Vignette development and assessment process. The figure shows the process by which the remote digital monitoring (RDM) vignettes were developed. Each of the 36 vignettes in our sample represents a possible combination of the selected RDM component modalities (3 × 6 × 2). Study participants could assess up to three different, randomly selected vignettes. EHR = electronic health record; CGM = continuous glucose monitoring; PA = physical activity.

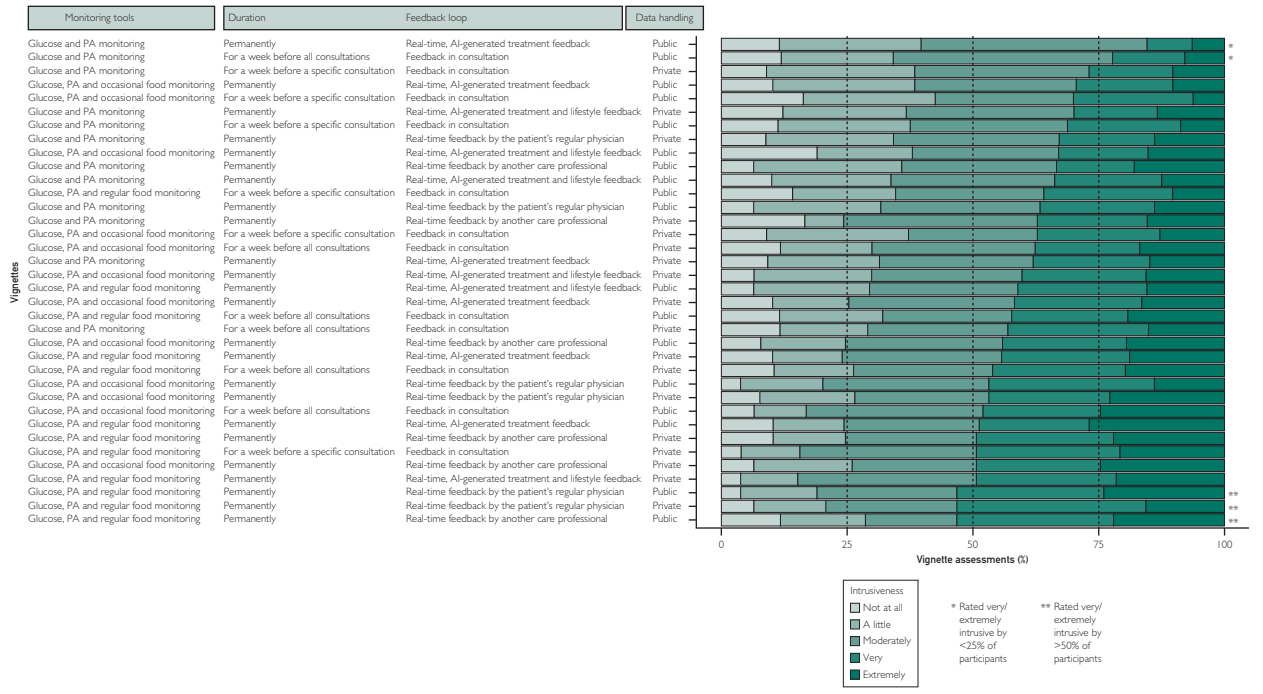

FIGURE 2. Intrusiveness of 2860 vignette-assessments. The figure shows participants' intrusiveness ratings for each of the 36 vignettes. Vignettes are ranked by the proportion of assessments rated very/extremely intrusive (from smallest to largest). This proportion ranged from 15% to 53% among vignettes describing different monitoring modalities. The asterisks mark the vignettes rated very/extremely intrusive by less than 25% of participants or by greater than 50% of participants. Overall, vignettes describing occasional or regular food monitoring and real-time feedback by the patients' regular physician or another care professional were considered more intrusive. However, ratings of the same vignette varied among participants. AI = artificial intelligence; PA = physical activity; RDM = remote digital monitoring.

3. Data handling, with two modalities: public-sector data handling (by a public-sector organization, eg, a public hospital) or private-sector data handling (by a private-sector organization, eg, an insurance or informatics company).

By making all possible combinations of these modalities, we developed 36 vignettes (see Supplemental Text 1 for a sample of vignettes, available online at http://www.mayoclinicproceedings.org).[25]

Data Collection

Each participant assessed three different, randomly selected vignettes of the total 36. For each vignette, participants assessed intrusiveness on a 5-point scale ("How intrusive would this monitoring be to your daily life?" Responses ranged from "not at all" to "extremely"). Participants additionally assessed the minimum required effectiveness for which they would adopt the RDM described in the vignette. These results are reported in a separate publication.[26]

After assessing all vignettes, participants were presented with two optional open-ended questions, which were used to identify drivers of intrusiveness (ie, factors that led participants to perceive RDM as intrusive): 1) "Which aspect of the monitoring scenarios did you find most intrusive and why?" and 2) "How would digital diabetes monitoring affect your family, social, and professional life?"

We collected participants' characteristics, including age, gender, diabetes type, insulin use, and current use of digital monitoring devices/software purposes.

The survey was initially drafted in English and translated to French by a bilingual speaker (TO). The translation was then

compared with the original version by two bilingual native French speakers (who were not directly involved in the study) to confirm that it reflected the original wording accurately. The survey was pilot-tested with three participants (two women with type 1 diabetes, and one man with type 2 diabetes). The participants were asked to provide feedback on survey completion time, ease of understanding study questions and identifying responses that represented their views, and technical aspects of navigating the study website. In addition, they were asked to propose any modifications they believed could increase the usefulness of the study for patients. On the basis of their feedback, the second open-ended question was added, and the questions on minimum required effectiveness were reworded.

Data Analysis

Data were analyzed with R v3.6.0. The unit of analysis was the individual vignette assessment. We included all participants who assessed one vignette or more.

The main outcome was the intrusiveness rating per complete vignette (pre-specified in the study protocol, available upon request by the authors). First, we present intrusiveness in the overall sample. In the main text, we group response points four and five in the 5-point scale for brevity (ie, "very intrusive" and "extremely intrusive"). To explore how intrusiveness varied among different vignettes (ie, how patients' perceptions varied among the different RDM scenarios), we present the number of vignettes with low intrusiveness (rated very/extremely intrusive by <25% of participants) and those with high intrusiveness (rated very/extremely intrusive by >50% of participants). To explore how intrusiveness varied among participants for the same RDM scenario, we present the number of vignettes that were rated simultaneously as 1) not at all intrusive by greater than or equal to 10% of participants and 2) extremely intrusive by greater than or equal to 10% of participants. The above-mentioned thresholds were defined by the authors to present the results succinctly. The full vignette rating data are available in Supplemental Table 1 (available online at http://www.mayoclinicproceedings.org).

Second, to assess the association between intrusiveness and RDM modalities and participant characteristics, we used a random-intercept, multivariable linear mixed model (LMM). We included person-specific random intercepts to account for correlation among an individual's survey responses. The dependent variable was intrusiveness (handled as a continuous variable). The independent variables were the three vignette factors and participant characteristics (age, insulin use, country of residence, number of hypoglycemic episodes in the last 30 days, self-reported diabetes control, current use of digital monitoring tools, and two Problem Areas in Diabetes scale items on guilt and burnout). A number identifying each study participant was used as a random intercept. Variable handling and model fit are further described in Supplemental Text 2 (available online at http://www.mayoclinicproceedings.org). We used multiple imputation by chained equations with 30 iterations for variables with missing data. We used the following predictors to impute missing data: age, gender, country of residence, diabetes type, whether the participant considered their diabetes to be well controlled or not, insulin use, and outcome data (intrusiveness and reassurance score). Continuous variables were imputed by using predictive means matching and categorical variables were imputed by using polytomous regression.

In addition, we performed two sensitivity analyses. First, we fit the model into the complete-case dataset. The characteristics of participants excluded from the complete-case dataset are presented in Supplemental Table 2 (available online at http://www.mayoclinicproceedings.org). Second, because the outcome variable is assessed on a 5-point scale, it could be analyzed as an integer or as an ordinal variable. Therefore, we applied a cumulative link mixed model (CLMM), which is well-suited for ordinal outcome data, in a sensitivity analysis. The same specifications were used in the LMM and CLMM (ie, independent variables, dependent

variables, and random effects term). The CLMM was applied in the imputed and the complete-case dataset. Finally, we conducted exploratory subgroup analyses of intrusiveness by insulin use and diabetes type.

The qualitative data were analyzed by using content analysis.[27] The flexibility of content analysis suits the topic because no preexisting framework exists for intrusiveness. We followed a systematic process: first, TO reviewed all data, then read several responses and tagged key concepts to form initial codes. A second author (AJ) independently coded 20% of responses following the same process. The authors met frequently to discuss discrepancies in coding until consensus was reached. New codes were created when needed. TO used the codes that emerged from the consensus to code the remaining responses. Finally, the authors clustered codes into themes according to their shared meaning,[28] and prevalence was estimated as the number of participants citing each code.

RESULTS

Overall, 1010 patients from 30 different countries participated in the survey by assessing at least one vignette (64% of study website visitors who gave informed consent to participate in the survey). They provided 2860 vignette assessments between February 1 and July 1, 2019 (each vignette was assessed a median of 78 times [interquartile range, 77 to 79 times]) (Supplemental Figure 1, available online at http://www.mayoclinicproceedings.org). Most participants were women (56.6%, n=572); the median age was 51 years (interquartile range, 37 to 63 years); approximately half had type 1 diabetes (51.9%, n=524); and many used insulin delivered by shots (38.6%, n=390) or pump (33.0%, n=333) (Table 1). The main countries of residence were France (35.6%, n=360), Canada (21.0%, n=212) and the United States (13.7%, n=138).

Intrusiveness

Overall, 39.6% (n=1135) of vignette assessments were rated very/extremely intrusive (ie, points four and five on the 5-point scale) (Figure 2). This proportion varied from 15.3% (n=12 of 78 assessments) to 53.2% (n=41 of 77 assessments) among vignettes describing different combinations of RDM modalities (Supplemental Table 1). Two vignettes were considered to have low intrusiveness: 1) glucose and physical activity (PA) monitoring permanently, with real-time, AI-generated treatment feedback and public-sector data handling; and 2) glucose and PA monitoring for a week before all consultations, with feedback in consultation and public-sector data handling. In contrast, three vignettes were considered to have high intrusiveness: 1) glucose, PA, and regular food monitoring permanently, with real-time feedback by another care professional and public-sector data handling; 2) glucose, PA, and regular food monitoring, permanently, with real-time feedback by the patient's regular physician and public-sector data handling; and 3) glucose, PA, and regular food monitoring, permanently, with real-time feedback by the patient's regular physician and private-sector data handling. Regarding variability of intrusiveness among participants, for the same RDM scenario, 15 of 36 vignettes were rated not at all intrusive by greater than or equal to 10% of participants and extremely intrusive by greater than or equal to 10% of participants.

In the LMM, the RDM modalities associated with increased intrusiveness were glucose, PA, and regular food monitoring (β=0.34; 95% CI, 0.26 to 0.42; $P<.001$); glucose, PA, and occasional food monitoring (β=0.25; 95% CI, 0.17 to 0.33; $P<.001$); permanently with real-time feedback by the patient's regular physician (β=0.25; 95% CI, 0.16 to 0.34; $P<.001$); and permanently with real-time feedback by another care professional (β=0.18; 95% CI, 0.09 to 0.28; $P<.001$) (Table 2). Public-sector data handling was associated with decreased intrusiveness (β=−0.15; 95% CI, −0.22 to −0.09; $P<.001$). The participant characteristic associated with increased intrusiveness was feeling burnt out by diabetes management (β=0.11; 95% CI, 0.05 to 0.17; $P=.001$). The participant characteristics associated with decreased intrusiveness were intending to use digital monitoring

TABLE 1. Participant Characteristics (n=1010)[a,b]

Characteristics	
Age, median (IQR) years	51 (37-63)
Gender	
Man	394 (39)
Woman	572 (57)
Prefers to self-describe	44 (4)
Country of residence[c]	
France	360 (36)
Canada	212 (21)
United States	138 (14)
Other	300 (30)
Diabetes type	
Type 1	524 (52)
Type 2	411 (41)
Other[d]	75 (7)
Uses insulin	
Insulin shots	390 (39)
Insulin pump	333 (33)
No insulin use	281 (28)
Hypoglycemic episodes experienced in past 30 days, median (IQR)[e]	3 (0-10)
Required assistance during a hypoglycemic episode in past 30 days[f]	40 (5)
Current use of digital monitoring tools for health or well-being purposes[f]	
Does not use them and does not intend to in the future	214 (26)
Intends to use them or uses them irregularly	142 (17)
Uses them regularly	465 (57)
PAID questionnaire items	
1. Feelings of guilt or anxiety when you get off track with your diabetes management[e]	
Not a problem	124 (15)
Minor problem	170 (20)
Moderate problem	249 (30)
Somewhat serious problem	210 (25)
Serious problem	79 (10)
2. Feeling "burned out" by the constant effort needed to manage diabetes[e]	
Not a problem	134 (16)
Minor problem	164 (20)
Moderate problem	253 (30)
Somewhat serious problem	183 (22)
Serious problem	100 (12)
3. Worrying about the future and the possibility of serious complications[e]	
Not a problem	50 (6)
Minor problem	121 (15)
Moderate problem	207 (25)
Somewhat serious problem	285 (34)
Serious problem	171 (21)

[a]IQR = interquartile range; PAID = Problem Areas in Diabetes scale.

[b]Values may not add to 100% due to rounding; values shown are n (%) unless otherwise stated.

[c]Other major country contributors include the United Kingdom (n=108), Ireland (n=82), New Zealand (n=31), and South Africa (n=18).

[d]The following diabetes types were reported by participants who responded with "other": Glucocorticoid-induced diabetes, maturity onset diabetes of the young, latent autoimmune diabetes of adulthood. Type 1.5, diabetes associated with cystic fibrosis, diabetes due to pancreatectomy (pancreatic cancer), secondary atypical insulin-treated.

[e]Estimated for n=834 of 1010 participants who completed the entire survey.

[f]Estimated for n=821 of 1010 participants without missing data.

tools or using them irregularly (β=−0.45; 95% CI, −0.62 to −0.28; $P<.001$) and using digital monitoring tools regularly (β=−0.20; 95% CI, −0.33 to −0.06; $P=.004$), feeling guilt or worry when diabetes management goes off track (β=−0.10; 95% CI, −0.16 to −0.04; $P=.001$), residing in Canada (β=−0.18; 95% CI, −0.34 to −0.02; $P=.03$), and male gender (β=−0.16; 95% CI, −0.29 to −0.03; $P=.01$) (model Akaike information criterion = 8151, R^2=0.091; semi-partial R2 provided in Supplemental Table 3, available online at http://www.mayoclinicproceedings.org).

The results of the LMM fit in the complete-case dataset are presented in Supplemental Table 4 (available online at http://www.mayoclinicproceedings.org). The model identified the same significant predictors as the LMM fit in the complete-case dataset, with the exception of residing in Canada (β=−0.18; CI −0.34 to −0.02; $P=.03$ in the imputed dataset, vs β=−0.14; 95%

TABLE 2. Linear Mixed Model of Intrusiveness Fit in the Imputed Dataset (n=2860)[a,b]

Predictors	n=2860		
	Estimates	95% CI	*P*
(Intercept)	2.26	2.02 to 2.50	<.001
Vignette-level predictors			
Monitoring tools (reference category: glucose and PA)			
Glucose, PA and regular food monitoring	0.34	0.26 to 0.42	<.001
Glucose, PA and occasional food monitoring	0.25	0.17 to 0.33	<.001
Duration/feedback loop (ref. cat.: For a week before a specific consultation, with feedback in consultation)			
Permanently, with real-time feedback by the patient's regular physician	0.25	0.16 to 0.34	<.001
Permanently, with real-time feedback by another care professional	0.18	0.09 to 0.28	<.001
Permanently, with real-time, artificial intelligence-generated treatment feedback	0.08	−0.01 to 0.17	.08
Data handling (ref. cat.: private-sector data handling)			
Public-sector data handling	−0.15	−0.22 to −0.09	<.001
Participant-level predictors			
Feeling "burned out" by the constant effort needed to manage diabetes (PAID questionnaire item)[b]	0.11	0.05 to 0.17	<.001
Feelings of guilt or anxiety when you get off track with your diabetes management (PAID questionnaire item)	−0.10	−0.16 to −0.04	.001
Current use of digital monitoring tools for health or well-being purposes (ref. cat.: does not use them and does not intend to)			
Intends to use them or uses them irregularly	−0.45	−0.62 to −0.28	<.001
Uses them regularly	−0.20	−0.33 to −0.06	.004
Well-controlled diabetes (self-reported)	0.12	−0.02 to 0.27	.08
Gender (ref. cat.: woman)			
Man	−0.16	−0.29 to −0.03	.01
Prefers to self-describe	0.05	−0.25 to 0.35	.75
Country of residence (ref. cat.: France)			
Canada	−0.18	−0.34 to −0.02	.03
Countries other than France, United States and Canada	−0.39	−0.54 to −0.25	<.001

[a]PA = physical activity; PAID = Problem Areas In Diabetes scale.

[b]*P* values estimated by Satterthwaite's two-sample *t* test for degrees of freedom; R^2=0.09, estimated with the r2glmm R package by using the standardized general variance approach.

CI, −0.31 to 0.04; *P*=.13 in the complete-case dataset). The sensitivity analysis by CLMM is presented in Supplemental Table 5 (available online at http://www.mayoclinicproceedings.org). We obtained similar results as by LMM in terms of significant predictors and magnitude of coefficients.

In subgroup analyses, participants who did not use insulin considered RDM, overall, less intrusive than those who used insulin shots or an insulin pump (35.6%, n=294 of 824, vs 39.9%, n=435 of 1089, and 42.5%, n=398 of 935 of vignette assessments rated very/extremely intrusive, respectively) (Supplemental Figure 2, available online at http://www.mayoclinicproceedings.org). Similarly, there were fewer vignettes with high intrusiveness in the non-insulin−use subgroup (three vs seven and eight, respectively). Intrusiveness ratings did not differ substantially between patients with type 1 and type 2 diabetes (41.7%, n=618 of 1481 and 39.1%, n=461 of 1179 of vignette assessments rated very/extremely intrusive, respectively) (Supplemental Figure 3, available online at http://www.mayoclinicproceedings.org).

Drivers of Intrusiveness Reported by Participants

Overall, 709 (70.2%) participants provided 1208 responses to the open-ended questions.

Content analysis resulted in 41 codes describing why RDM was considered intrusive by participants, clustered in four overarching themes: burden, control, data safety and misuse, and dehumanization of care (Supplemental Figure 4, Supplemental Table 6, available online at http://www.mayoclinicproceedings.org).

Burden encompassed practical and psychosocial aspects of burden as drivers of intrusiveness (reported by n=468). Practical burdens were related to the physical obtrusiveness associated with wearing a CGM device or carrying a smartphone and with the time-consuming tasks the patient would have to perform, particularly for food monitoring:

"Photographing my food would add another step to the faffing [wasting time] with glucose monitoring and an injection at every meal." (38-year-old woman, type 1 diabetes)

Intrusiveness was also attributed to psychosocial burdens stemming from the visibility of RDM tools and monitoring behaviors, which were seen as too awkward to perform in public (eg, at work and in restaurants). Participants highlighted the consequences of attracting attention to their RDM in public, including having their diabetes diagnosis unwillingly disclosed to others: "The sensor on [the] arm at all times. I would get lots of questions when people see it for [the] first time." (63-year-old man, type 2 diabetes)

The second driver of intrusiveness concerned participants' perceived lack of control (n=440). Participants expressed the desire for control over RDM (eg, the ability to block physician feedback). Some reported that RDM would intrude upon their privacy by making them feel "under surveillance," limiting their autonomy to adjust their treatment, and revealing poor diabetes management behaviors to care professionals who may be judgmental. This is in agreement with the results of the LMM, in which real-time feedback by a health care professional were associated with increased intrusiveness: "Wearing a sensor gives me the impression of being constantly under surveillance, of being unable to have a minor slip-up without it being visible in the daily [glucose] curve, while it would have gone more or less unnoticed with glycated hemoglobin." (47-year-old woman, type 1 diabetes)

Fears around data safety and misuse included worry about data leaks or about the data being intentionally used for purposes other than health care (eg, targeted marketing, n=206). For many participants, these concerns were linked to the involvement of private-sector organizations. This reflects our quantitative findings on the association of public-sector data handling with lower intrusiveness: "Data handling by a private organization … Can we be sure that our health data will not be monetized, for example, by health insurance companies?" (62-year-old man, type 2 diabetes)

Finally, participants reported the dehumanization of patients, who may feel reduced to their monitoring data (n=34): "The constant impression of being a lab rat and that my diabetes data are trivialized… To be just one case among millions…. It's missing the human dimension." (46-year-old woman, type 1 diabetes)

DISCUSSION

This international study found that participants perceive RDM as more intrusive when it includes food monitoring, real-time feedback by a care professional, and private-sector data handling. AI-generated feedback was considered less intrusive than real-time feedback by a professional, possibly because AI is perceived as non-judgmental.[29] Indeed, the qualitative analysis identified concerns about constant surveillance impeding patients' autonomy.

Perceptions of intrusiveness for the same RDM modalities vary among participants. Participants who currently used digital monitoring tools or intended to use them in the future and those who felt more guilt or worry considered RDM less intrusive. Participants who felt more burnt out by diabetes management considered RDM more intrusive. These findings indicate a relationship between intrusiveness and patients' current experiences of treatment

burden, health worry, and negative attitudes toward digital technologies. Further variability not captured by the model may be attributed to unmeasured participant characteristics, such as patients' need for autonomy.

Our findings agree with a synthesis of qualitative studies of RDM that identified similar burdens and concerns.[30−32] Some studies found high satisfaction and fewer hassles associated with CGM use than usual care.[19,33,34] However, these studies predominantly focused on CGM without behavior monitoring and did not include real-time feedback loops, unlike the vignettes assessed in this study.

This study is strengthened by its large, international sample from countries with different health care systems in the Western world. Having a median number of 78 assessments per vignette allowed for precise estimates of their intrusiveness. This allowed us to attribute the observed variability in ratings assigned to the same vignette to different perceptions by participants. The use of vignettes allowed us to compare 36 diverse RDM scenarios (eg, including physiological and behavioral monitoring and feedback with different degrees of automation, ie, provided by AI instead of humans). We used systematic, established methods of qualitative data collection and analysis (analysis of all available data, independent duplication and consensus, transparent reporting of all codes with verbatim).[35]

IMPLICATIONS FOR CLINICAL PRACTICE

The findings of this study can inform the design and implementation of RDM. First, there is a need for minimally disruptive RDM design (eg, by creating microsensors that are not publicly visible). Second, we identified substantial variability among individual participants in terms of the RDM modalities they consider intrusive, which should be taken into account by physicians. To help patients make sense of RDM, physicians could use shared decision-making aids similar to the vignettes used in this study. Third, even in the presence of minimally disruptive technology, physicians may be required to manage barriers that arise from their relationship with patients with diabetes, such as the social desirability associated with nutrition patterns.

Finally, the digital revolution has been considered a step toward reducing the treatment burden for patients with diabetes.[36] Our findings imply that RDM does not simply add or subtract burdens but rather transforms them. As health care enters the private sphere, social aspects of the burdens that have been identified in the literature may become more pronounced.[37] For example, monitoring tasks have a different significance for some patients when they disrupt socially intimate experiences, such as the family dinner. For patients who consider receiving feedback from a health care professional as revoking their control over their diabetes management, digital monitoring may represent a step away from patient-centered care. Clinical studies of RDM usability and satisfaction should assess these emerging aspects of burden.

Study Limitations

This study also has limitations. Our sample is not representative of the global population of patients with diabetes. However, a representative sample of this size would have led to small subgroups of populations for which RDM is highly relevant (eg, patients with type 1 diabetes). Because we aimed to identify determinants of patients' perceptions, we sought to recruit a diverse sample in terms of characteristics that might determine perceptions of intrusiveness. We used an LMM to identify predictors of intrusiveness. LMM is suited for continuous data, but intrusiveness can also be analyzed as an ordinal outcome. However, we performed a sensitivity analysis by using CLMM, for which the assumed outcome data are ordinal. Results were comparable between the LMM and CLMM. Finally, the vignettes offer short descriptions of RDM. In real life, physicians would discuss RDM with patients in detail. However, our aim was not to precisely simulate a clinical context but to broadly capture patients' perceptions of the many forms RDM can take.

CONCLUSION

Patients perceive RDM as more intrusive when it includes occasional or regular food monitoring, real-time feedback by their regular physician or another care professional, and private-sector data handling. Minimally disruptive RDM design could help reduce intrusiveness, and shared decision-making could help patients identify the RDM that best aligns with their values and lifestyle.

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SUPPLEMENTAL ONLINE MATERIAL

Supplemental material can be found online at http://www.mayoclinicproceedings.org. Supplemental material attached to journal articles has not been edited, and the authors take responsibility for the accuracy of all data.

Abbreviations and Acronyms: **AI** = artificial intelligence; **PA** = physical activity; **RDM** = remote digital monitoring

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Part 2: Assessing the relationship between intrusiveness and willingness to adopt DBCIs

In the first project of this thesis, we examined patient's perceptions of intrusiveness of complex RDM interventions for diabetes. We identified modalities that are associated with increased perceived intrusiveness. The next step was to examine whether intrusiveness might be associated with patients' willingness to adopt RDM.

Our interest in quantifying the relationship between these two variables was motivated by the fact that so far, no studies have assessed the association between intrusiveness and willingness to adopt DBCIs. However, in some qualitative studies, participants have justified their decision to not use monitoring by citing intrusiveness.[39,56] For example, participants in the interview study by Oudshoorn reported being unwilling to use monitoring devices with audio alerts in public, because the alerts would attract strangers' attention, leading the patient to feel uncomfortable at their illness being "revealed" to others.[39]

In this perspective, intrusiveness represents a psychological cost patients have to pay to reap the benefits of DBCIs. Previous studies show that patients make the decision to follow a treatment by weighing its benefits against its costs,[57,58] and that costs include the impact of the treatment on the patient's life (e.g., risk of side-effects, treatment burden the patient might experience by adding a new treatment to their care). If the costs exceed the benefits, as perceived by the patient, the patient may decide to not adopt or adhere to the treatment.[57,58] We could therefore hypothesize that as the cost of intrusiveness increases due to specific RDM modalities, patients would demand that the benefit

increases too, in order to adopt it. The more intrusive RDM is, the greater health benefits it must offer to be acceptable.

In comparison to digital therapeutics that deliver pharmacologic treatments, DBCI components present an interesting case of cost-benefit calculation. Pharmacologic digital therapeutics may reduce the tasks patients have to perform, potentially reducing treatment burden and the intrusiveness of the treatment in the patient's life. For example, the artificial pancreas (a closed-loop system in which insulin dosage is adapted based on data from continuous glucose monitoring sensors and delivered automatically to the patient by a wearable insulin pump), removes the need for frequent glucose measurement by finger-prick test and manual calculation of the correct insulin dose. Thereby, the artificial pancreas removes tasks that are disruptive and awkward to perform in public. On the other hand, behavioral monitoring and interventions are usually not part of chronically ill patients' treatment. Not only might DBCI components not reduce patients' workload, but they may add tasks to the patient's workload. These tasks may be particularly intrusive due to the stigma associated with some behaviors for some chronic conditions (e.g., the stigma associated with nutrition and weight for patients with type 2 diabetes might make food monitoring particularly intrusive). We could hypothesize that the addition of behavioral intervention components to a pharmacologic digital intervention may lead to a less favorable cost-benefit profile.

Our second study aimed to assess the relationship between different RDM modalities, intrusiveness, and the minimum required benefit for which the patient would adopt RDM. This study used data collected from 1010 participants in the survey described in the previous chapter.

Briefly, for each vignette, participants assessed the minimum required effectiveness for two different health outcomes (one short- and one long-term outcome), for which they would adopt RDM in place of their current care. The short-term outcome question was: "How effective would this monitoring have to be in reducing the frequency of hypoglycemic episodes for you to choose it over your current way of monitoring?" The long-term outcome question was: "How effective would this monitoring have to be in preventing eye complications in the future for you to choose it over your

current way of monitoring? Participants responded using a 5-point scale, from “It could be much less effective than my usual care” to “It would have to be much more effective than my usual care”. The middle point (3 of 5) was labelled “It would have to be just as effective as my usual care”. We examined the association of the outcomes with intrusiveness, RDM characteristics, and demographic and illness-related participant characteristics. In addition, we performed subgroup analyses by insulin use and type of diabetes. We chose these characteristics for our subgroup analyses because we considered that these variables distinguished participants in groups with different treatment plans and monitoring behaviors, which may in turn affect willingness to change these behaviors by adopting a digital care modality

We found that participants required greater effectiveness for both short- and long- term outcomes to adopt RDM they considered more intrusive. In terms of RDM modalities, participants required greater effectiveness to adopt RDM that included occasional or regular food monitoring compared to glucose and PA monitoring alone, and RDM that included permanent monitoring with real-time feedback by a physician or real-time AI-generated treatment feedback, as compared with short-term use with feedback in consultation.

These findings have two important implications for the study of DBCIs. First, we found that similar to ratings of intrusiveness, the ratings of required effectiveness for the same RDM components vary substantially among individuals. In addition, perceived intrusiveness is associated with patients’ expecting greater health benefits to adopt RDM. This means that physicians who implement (i.e., recommend or prescribe) DBCIs to their patients have to take into account that the same intervention may be perceived entirely differently by different patients, due to personal characteristics, different perceptions of intrusiveness, and different expectations for health benefits. Physician-patient dyads should discuss the expected efficacy of DBCIs and the ways in which the DBCI fits with patients’ life routines and values, to identify the type of DBCI that best aligns with each patient’s profile. To do this, physicians may use summaries of key DBCI characteristics, similar to the vignettes used in our study, as shared decision making-aids. Second, the fact that intrusiveness is associated with

greater health benefit requirement to adopt DBCIs points to the reduction of intrusiveness as a means of increasing DBCI adoption. As discussed in the previous chapter, the findings of our first study point to specific ways of reducing intrusiveness through better digital monitoring tool design and by improving the patient-physician relationship.

These findings were obtained from the survey on intrusiveness, described in the previous chapter. As such, they are subject to the above-described limitations regarding the composition of the sample, the choice of a vignette rating task as opposed to a DCE, and the lack of information regarding patients' economic status and ethnicity.

The results of this study have been reported in: *Oikonomidi T, Ravaud P, Cosson E, Montori V, Tran VT. Evaluation of patient willingness to adopt remote digital monitoring for diabetes management. JAMA network open. 2021 Jan 4;4(1):e2033115*. The online supplement files of the article are presented in Annex 2 of this thesis.

JAMA Network Open

Original Investigation | Diabetes and Endocrinology

Evaluation of Patient Willingness to Adopt Remote Digital Monitoring for Diabetes Management

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Abstract

IMPORTANCE Patients will decide whether to adopt remote digital monitoring (RDM) for diabetes by weighing its health benefits against the inconvenience it may cause.

OBJECTIVE To identify the minimum effectiveness patients report they require to adopt 36 different RDM scenarios.

DESIGN, SETTING, AND PARTICIPANTS This survey study was conducted among adults with type 1 or type 2 diabetes living in 30 countries from February to July 2019.

EXPOSURES Survey participants assessed 3 randomly selected scenarios from a total of 36. Scenarios described different combinations of digital monitoring tools (glucose, physical activity, food monitoring), duration and feedback loops (feedback in consultation vs real-time telefeedback by a health care professional or by artificial intelligence), and data handling modalities (by a public vs private company), reflecting different degrees of RDM intrusiveness in patients' personal lives.

MAIN OUTCOMES AND MEASURES Participants assessed the minimum effectiveness for 2 diabetes-related outcomes (reducing hypoglycemic episodes and preventing ophthalmologic complications) for which they would adopt each RDM (from much less effective to much more effective than their current monitoring).

RESULTS Of 1577 individuals who consented to participate, 1010 (64%; 572 [57%] women, median [interquartile range] age, 51 [37-63] years, 524 [52%] with type 1 diabetes) assessed at least 1 vignette. Overall, 2860 vignette assessments were collected. In 1025 vignette assessments (36%), participants would adopt RDM only if it was much more effective at reducing hypoglycemic episodes compared with their current monitoring; in 1835 assessments (65%), participants would adopt RDM if was just as or somewhat more effective. The main factors associated with required effectiveness were food monitoring (β = 0.32; SE, 0.12; P = .009), real-time telefeedback by a health care professional (β = 0.49; SE, 0.15; P = .001), and perceived intrusiveness (β = 0.36; SE, 0.06; P < .001). Minimum required effectiveness varied among participants; 34 of 36 RDM scenarios (94%) were simultaneously required to be just as or less effective by at least 25% of participants and much more effective by at least 25% of participants. Results were similar for participant assessments of scenarios regarding the prevention of ophthalmologic complications.

CONCLUSIONS AND RELEVANCE The findings of this study suggest that patients require greater health benefits to adopt more intrusive RDM modalities, food monitoring, and real-time feedback by a health care professional. Patient monitoring devices should be designed to be minimally intrusive. The variability in patients' requirements points to a need for shared decision-making.

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Key Points

Question What is the minimum effectiveness at which patients would adopt different remote digital monitoring (RDM) modalities for managing diabetes?

Findings In this survey study of 1010 adults with diabetes from 30 countries, 65% reported that they would adopt RDM even if it offered no or modest health improvements compared with their current monitoring. Participants reported that they required RDM to be more effective when they perceived it as intrusive to their lives and when it included food monitoring or real-time feedback by a health care professional.

Meaning These findings suggest that physicians should help patients select RDM modalities that align with their preferences and are unobtrusive to their lifestyle to ensure RDM adoption.

+ Supplemental content

Author affiliations and article information are listed at the end of this article.

Introduction

Remote digital monitoring (RDM) is a novel care modality that is being implemented in clinical settings because of its potential benefits for improving health outcomes.[1-7] RDM consists of using prescribed sensors to capture patients' physiological and behavioral data, which can then be transmitted to their physician to complement in-person consultations or be used to offer real-time feedback provided by artificial intelligence (AI) or a clinician.[4,8-13]

As with other treatment decisions, patients decide whether to adopt RDM by weighing its benefits against its costs and inconveniences.[14] Previous studies have identified the costs of RDM, including disruptive alerts and social stigma,[15-17] which represent the intrusiveness of RDM in patients' private lives.[18,19] Intrusiveness can lead to nonadherence to RDM among some patients,[15,16] but others may decide to adopt RDM despite its intrusiveness to obtain superior health benefits than those offered by the traditional care model.[20] The magnitude of health benefits patients require to adopt RDM and the association of this requirement with the perceived intrusiveness of RDM has not been explored. To address this gap, we performed a vignette-based survey to identify the minimum effectiveness required by patients with type 1 or 2 diabetes to adopt different RDM scenarios with varying degrees of intrusiveness.

Methods

We designed a vignette-based survey. In vignette-based surveys, participants are asked to assess a series of vignettes on a given topic. Vignettes are hypothetical scenarios in which key components (vignette factors) are varied systematically to take 1 of several prespecified options (factor levels). This allows researchers to examine participants' assessment of both the complete vignettes and each factor level. Our vignettes described potential applications of RDM for diabetes delivered as part of patients' usual care.

Vignette-based surveys have been widely used to examine perceptions and stated preferences.[21] The stated preference elicited with vignettes has been validated against real-world behavior, including behaviors with high desirability bias.[22-24]

Participants

A nonprobability, convenience sample of Anglophone and Francophone adults with type 1 or 2 diabetes was recruited between February and July 2019 by (1) disseminating information about the study on patient forums, Facebook groups, and diabetes-related websites; (2) email invitation to participants of the French e-cohort ComPaRe,[25] a citizen-science project in which patients can register to participate in research; and (3) in-person recruitment in the Endocrinology Department of the Mayo Clinic (Rochester, Minnesota). By recruiting participants via different channels, we aimed to avoid a highly select sample.

Patients were directed to the study website,[26] where they were shown a standard information sheet reporting the purpose of the study, participants' rights and obligations, potential harms from participation, intended statistical treatment of the collected data and publication of the results, and the contact information of the researchers. After reading the information sheet, participants could select to consent to participate (this option allowed participants to access the survey questionnaire) or refuse to participate (this options led to the participant exiting the study website). The protocol was reviewed by the ethics committee of the French National Institute of Health and Medical Research, and it is available from the corresponding author. This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline.

Vignette Development

First, 3 authors (T.O., P.R., V.T.T.) selected the following vignette factors and factor levels with which to develop the study vignettes, based on a review of monitoring tools available on the market and by consultation with a panel of diabetologists:

- Monitoring tools could take 1 of the following 3 levels: (1) glucose and physical activity (PA) monitoring alone; (2) glucose, PA, and occasional food monitoring, or (3) glucose, PA, and regular food monitoring.
- Duration and feedback loop could take 1 of the following 6 levels: (1) monitoring for a week before a specific consultation with feedback in consultation; (2) monitoring for a week before all consultations with feedback in consultation; (3) monitoring permanently with real-time feedback from the patient's regular physician; (4) monitoring permanently with real-time feedback by another care professional; (5) monitoring permanently with real-time, AI-generated treatment feedback; or (6) monitoring permanently with real-time, AI-generated treatment plus lifestyle feedback.
- Data handling could take 1 of the following 2 levels: data handling by (1) a public-sector organization (eg, public hospital) or (2) a private-sector organization (eg, insurance company).

These modalities were combined in all possible ways to develop 36 complete vignette scenarios (eAppendix 1 in the Supplement).

Data Collection

Each participant assessed 3 randomly selected vignettes by responding to 2 questions, indicating the minimum health benefit they would require to adopt the RDM as their usual care. The first question was, "How effective would this monitoring have to be in reducing the frequency of hypoglycemic episodes for you to choose it over your current way of monitoring?" The second question was, "How effective would this monitoring have to be in preventing eye complications in the future for you to choose it over your current way of monitoring?"

Participants responded using a 5-point scale (from "it could be much less effective" to "it would have to be much more effective"). We used 2 questions referring to a short-term and long-term health outcomes because people may be biased toward short-term rewards.[27]

We collected participants' demographic characteristics and diabetes-related data as well as their perceived intrusiveness for each vignette to examine the association between intrusiveness and minimum required effectiveness (eAppendix 2 in the Supplement). Exploring the association between RDM modalities and intrusiveness was a separate objective and is reported in a different paper.[28]

Statistical Analysis

Data were analyzed with R version 3.6.0 (R Project for Statistical Computing). Statistical significance was set at $P < .05$, and all tests were 2-tailed. The unit of analysis was the vignette assessment. All participants who assessed at least 1 vignette were included in the analyses.

In simple linear regression, 10 to 30 observations are required per included independent variable.[29] Accounting for clustering (each participant was asked to evaluate 3 vignettes), we estimated that we needed 900 vignette evaluations from 300 participants.

First, we present the results for minimum required effectiveness required by participants to adopt RDM. In calculating summary statistics we grouped the following response points, which indicate that participants would adopt RDM even if it was no more effective than their current monitoring: "it could be much less effective," "it could be somewhat less effective," and "it would have to be just as effective." The full data are available in eTable 1 in the Supplement. To explore how participants' ratings varied for the same vignette, we present the number of vignettes that were simultaneously required to be just as effective as or less effective than their current monitoring by at least 25% of participants and much more effective than their current monitoring by at least 25% of participants. These thresholds were defined by the authors to present the results succinctly.

Second, we fit 2 random-intercept multivariable cumulative-link mixed models (CLMMs) to assess the association between minimum required effectiveness (as a variable with 5 levels) and the vignette factor levels, perceived vignette intrusiveness, and participant characteristics. A number identifying each participant was used as a random intercept to account for clustering. We used multiple imputation for variables with missing data. We performed a sensitivity analysis by applying the CLMM in the complete-case data set. Variable handling and model fit are described in eAppendix 3 in Supplement. Finally, we present the minimum required effectiveness by subgroups of insulin use and diabetes type.

Results

Overall, 1010 of 1577 individuals (64%) who consented to participate assessed at least 1 vignette; 572 (57%) were women; and the median (interquartile range [IQR]) age was 51 (37-63) years (**Table 1**). This resulted in 2860 vignette assessments between February and July 2019 (median [IQR] assessments per vignette, 78 [77-79]) (eFigure 1 in the Supplement). Regarding clinical characteristics, 524 participants (52%) had type 1 diabetes; 723 (72%) used insulin; and 687 (68%) considered their diabetes controlled (Table 1). In terms of diabetes-related complications, 363

Table 1. Participant Characteristics

Characteristic	Participants, No. (%) (N = 1010)[a]
Age, median (IQR), y	51 (37-63)
Gender	
Men	394 (39)
Women	572 (57)
Prefers to self-describe	44 (4)
Country of residence	
France	360 (36)
Canada	212 (21)
United States	138 (14)
Other	300 (30)
Diabetes type	
Type 1	524 (52)
Type 2	411 (41)
Other[b]	75 (7)
Uses insulin	
Insulin shots	390 (39)
Insulin pump	333 (33)
No insulin use	281 (28)
Hypoglycemic episodes experienced in past 30 d, median (IQR), No.[c]	3 (0-10)
Required assistance during a hypoglycemic episode in past 30 d[c]	40 (5)
Current use of digital monitoring tools for health or well-being purpose[d]	
Does not use them and does not intend to in the future	214 (26)
Intends to use them or uses them irregularly	142 (17)
Uses them regularly	465 (57)

[a] Values may not add to 100% due to rounding.

[b] Other major country contributors were the United Kingdom (108 participants), Ireland (82 participants), New Zealand (31 participants), and South Africa (18 participants).

[c] Estimated for 834 of 1010 participants without missing data.

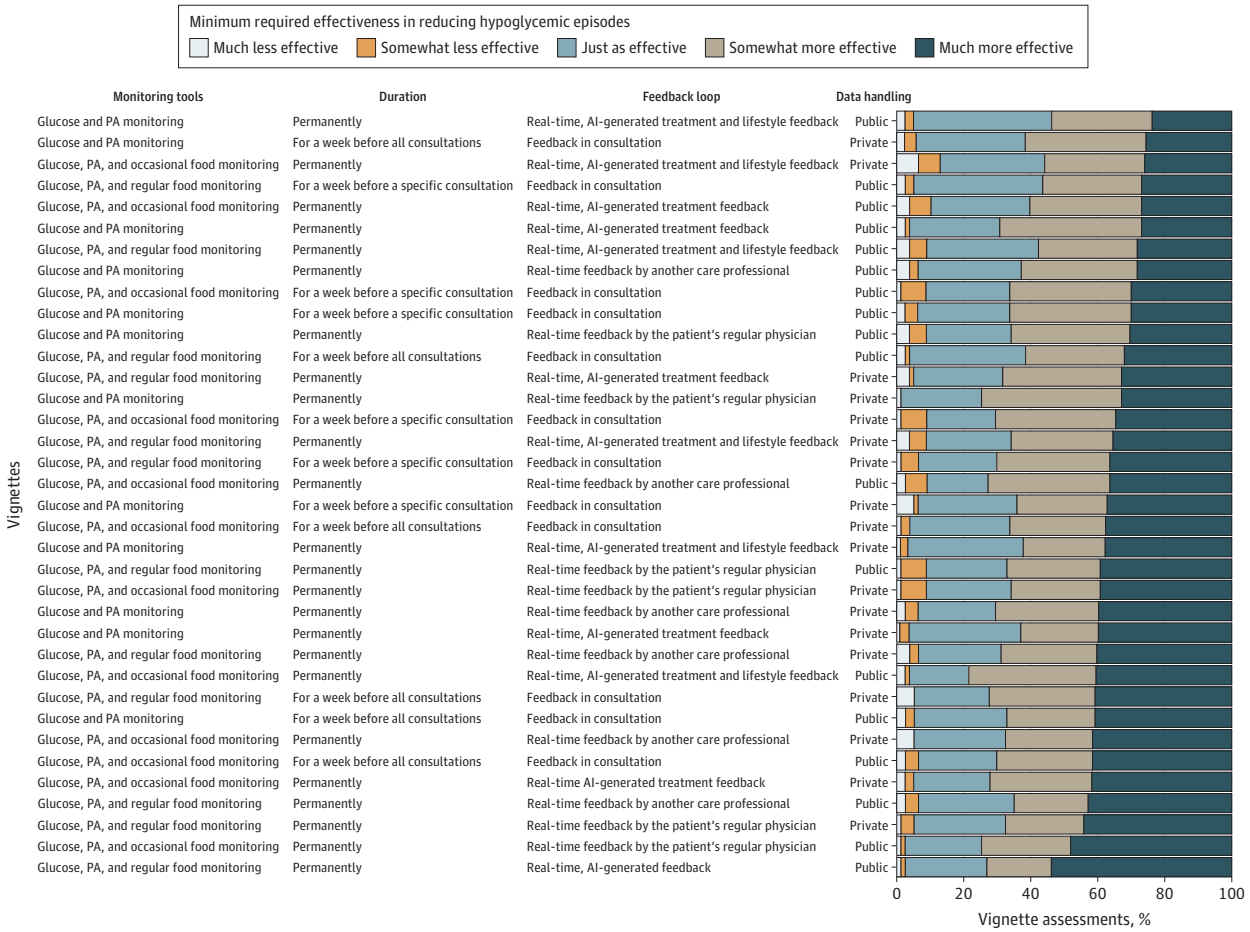
[d] Estimated for 821 of 1010 participants without missing data.

patients (36%) had neuropathy, 141 (14%) had kidney failure, 45 (4%) had had a heart attack, 30 (3%) had blindness, and 21 (2%) had had a stroke, with some participants reporting more than 1 complication. Participants resided in 30 countries, predominantly France (360 [36%]). Regarding questionnaire items about problem areas in diabetes, 283 of 834 participants (34%) with complete data reported that feeling burned out by the effort needed to manage diabetes posed a somewhat serious or serious problem, and 456 (55%) reported that worrying about the future and the possibility of serious complications posed a somewhat serious or serious problem.

Minimum Required Effectiveness to Adopt RDM

Participants would adopt RDM in 1835 assessments (65%) if it was just as effective or less effective (959 [34%]) or somewhat more effective (876 [31%]) than their current monitoring in reducing hypoglycemic episodes, and in 1025 (36%) if it was much more effective (**Figure 1**; eTable 1 in the Supplement). Participants' ratings of minimum required effectiveness varied among different vignettes. The vignette with the lowest minimum required effectiveness contained glucose and PA monitoring permanently with real-time, AI-generated treatment and lifestyle feedback and public-sector data handling. Regarding variability among participants' views of the same RDM, 34 of 36 vignettes (94%) were simultaneously required to be just as or less effective by at least 25% of participants and much more effective by at least 25% of participants.

Figure 1. Minimum Required Effectiveness at Reducing Hypoglycemic Episodes for the Adoption of Remote Digital Monitoring in 2860 Vignette Assessments



Vignettes are ranked by the proportion of assessments requiring that remote digital monitoring be much more effective. Ratings varied depending on the contents of remote digital monitoring described in different vignettes, and they varied among participants for the same vignette. AI indicates artificial intelligence; PA, physical activity.

Results were similar for preventing ophthalmologic complications (**Figure 2**). Participants would adopt RDM in 925 assessments (32%) if it was just as effective as or less effective than their current monitoring, in 922 (32%) if it was somewhat more effective, and in 1013 (35%) if it was much more effective. We observed variability among participants' views of the same RDM in 33 of 36 vignettes (92%).

Factors Associated With Minimum Required Effectiveness

Minimum required effectiveness at reducing hypoglycemic episodes was positively associated with the following vignette-level factors: RDM intrusiveness (β = 0.36; SE, 0.06; $P < .001$); glucose, PA, and occasional food monitoring (β = 0.32; SE, 0.12; $P = .009$); glucose, PA, and regular food monitoring (β = 0.28; SE, 0.12; $P = .02$); permanent monitoring with real-time feedback by the patient's regular physician (β = 0.32; SE, 0.15; $P = .03$) or by another care professional (β = 0.49; SE, 0.15; $P = .001$); and permanent monitoring with real-time AI-generated treatment feedback (β = 0.42; SE, 0.14; $P = .004$) (**Table 2**). In terms of participant-level factors, minimum required effectiveness at reducing hypoglycemic episodes was associated with use of insulin shots (β = 0.81; SE, 0.27; $P = .003$) and an insulin pump (β = 1.1; SE 0.29; $P < .001$) (Akaike information criterion [AIC], 6195; $R^2 = 0.04$).

Minimum required effectiveness at preventing ophthalmologic complications was positively associated with the following vignette-level factors: RDM intrusiveness (β = 0.36; SE, 0.06;

Figure 2. Minimum Required Effectiveness at Preventing Ophthalmologic Complications for the Adoption of Remote Digital Monitoring in 2860 Vignette Assessments

Vignettes are ranked by the proportion of assessments requiring that remote digital monitoring be much more effective. Ratings varied depending on the contents of the remote digital monitoring described in different vignettes, and they varied among participants for the same vignette. AI indicates artificial intelligence; PA, physical activity.

$P < .001$); glucose, PA, and occasional food monitoring (β = 0.27; SE, 0.13; $P = .03$); and permanent monitoring with real-time feedback by a care professional besides the participant's regular physician (β = 0.48; SE, 0.14; $P = .001$) (Table 2). In terms of participant-level factors, it was associated positively with worry about future complications (β = 0.36; SE, 0.11; $P = .001$), use of insulin shots (β = 0.67; SE 0.31; $P = .03$), and use of an insulin pump (β = 0.68; SE, 0.32; $P = .04$) and negatively with residing in the United States (β = −1.17; SE, 0.39; $P = .003$) (AIC, 5863; $R^2 = 0.04$).

Table 2. Cumulative Link Mixed Model of the Required Effectiveness Outcomes from 2860 Vignette Assessments

	Reducing hypoglycemic episodes[a]			Preventing ophthalmologic complications[b]		
Factor	β (SE)	OR (95% CI)	*P* value	β (SE)	OR (95% CI)	*P* value
Much less or somewhat less	-5.48 (0.43)	0.00 (0.00 to 0.01)	<.001	-7.12 (0.49)	0.00 (0.00 to 0.00)	<.001
Somewhat less or just as	-3.85 (0.4)	0.02 (0.01 to 0.05)	<.001	-5.31 (0.45)	0.00 (0.00 to 0.01)	<.001
Just as or somewhat more	0.16 (0.38)	1.17 (0.56 to 2.45)	.68	-0.74 (0.42)	0.48 (0.21 to 1.10)	.08
Somewhat more or much more	2.95 (0.39)	19.08 (8.96 to 40.63)	<.001	2.53 (0.43)	12.49 (5.39 to 28.96)	<.001
Vignette-level factors						
Monitoring tools						
Glucose and PA	NA	1 [Reference]	NA	NA	1 [Reference]	NA
Glucose, PA, and regular food monitoring	0.28 (0.12)	1.33 (1.05 to 1.69)	.02	0.24 (0.13)	1.28 (0.99 to 1.64)	.06
Glucose, PA, and occasional food monitoring	0.32 (0.12)	1.37 (1.08 to 1.74)	.009	0.27 (0.13)	1.31 (1.02-1.68)	.03
Duration an d feedback loop						
1 Week, with feedback given in consultation	NA	1 [Reference]	NA	NA	1 [Reference]	NA
Permanently, with real-time feedback by the patient's regular physician	0.32 (0.15)	1.38 (1.03 to 1.84)	.03	0.23 (0.14)	1.26 (0.95 to 1.66)	.11
Permanently, with real-time feedback by another care professional	0.49 (0.15)	1.64 (1.21 to 2.20)	.001	0.48 (0.14)	1.62 (1.22 to 2.15)	.001
Permanently, with real-time, artificial intelligence-generated treatment feedback[c]	0.42 (0.14)	1.52 (1.15 to 2.02)	.004	NA	NA	NA
Permanently, with real-time, artificial intelligence-generated treatment and lifestyle feedback[c]	0.17 (0.15)	1.18 (0.89 to 1.58)	.25	NA	NA	NA
Intrusiveness rating	0.36 (0.06)	1.44 (1.29 to 1.60)	<.001	0.36 (0.06)	1.44 (1.28 to 1.62)	<.001
Participant characteristics						
Use of monitoring tools						
Does not use them and does not intend to	NA	1 [Reference]	NA	NA	1 [Reference]	NA
Intends to use them for health or well-being purposes or uses them irregularly	-0.4 (0.25)	0.67 (0.41 to 1.08)	.10	- 0.46 (0.27)	0.63 (0.37 to 1.08)	.09
Feeling burned out by the constant effort needed to manage diabetes[c]	0.2 (0.11)	1.22 (0.98 to 1.51)	.07	NA	NA	NA
Worrying about the future and the possibility of serious complications	0.17 (0.12)	1.18 (0.94 to 1.49)	.15	0.36 (0.11)	1.43 (1.15 to 1.78)	.001
Insulin use						
None	NA	1 [Reference]	NA	NA	1 [Reference]	NA
Insulin shots	0.81 (0.27)	2.24 (1.31 to 3.83)	.003	0.67 (0.31)	1.96 (1.07 to 3.59)	.03
Insulin pump	1.1 (0.29)	2.99 (1.69 to 5.28)	<.001	0.68 (0.32)	1.97 (1.04 to 3.72)	.04
Country of residence						
France	NA	1 [Reference]	NA	NA	1 [Reference]	NA
Countries other than France, United States, and Canada[d]	-0.33 (0.35)	0.50 (0.29 to 0.85)	.01	-1.29 (0.31)	0.27 (0.15 to 0.51)	<.001
United States	-0.21 (0.3)	0.72 (0.36 to 1.42)	.34	-1.17 (0.39)	0.31 (0.14 to 0.67)	.003
Canada	-0.69 (0.27)	0.81 (0.45 to 1.47)	.49	-0.41 (0.35)	0.67 (0.34 to 1.32)	.24
Gender[c,e]						
Woman	NA	1 [Reference]	NA	NA	1 [Reference]	NA
Prefers to self-describe	-0.25 (0.53)	0.78 (0.28 to 2.20)	.64	NA	NA	NA

Abbreviations: NA, not applicable; OR, odds ratio; PA, physical activity; SE, standard error.

[a] Akaike information criterion, 6195; pseudo-$R^2 = 0.04$ (estimated for the model vs the null using Nagelkerke method). *P* values estimated by Satterthwaite 2-sample *t* test for degrees of freedom.

[b] Akaike information criterion, 5863; pseudo-$R^2 = 0.04$ (estimated for the model vs the null using Nagelkerke method).

[c] This variable was not included in the final model for minimum required effectiveness in preventing ophthalmologic complications.

[d] Other major country contributors were the United Kingdom, Ireland, New Zealand, and South Africa.

[e] The category men was removed in stepwise model fitting.

The sensitivity analysis in the complete-case data set is presented in eTable 2 in the Supplement. For the minimum required efficacy in reducing hypoglycemic episodes, the model identified the same factors as in the imputed data set, with the exception of permanent monitoring with real-time feedback by the patient's regular physician. For the minimum required efficacy in preventing ophthalmologic complications, the model identified the same factors as in the imputed data set, with the exception of glucose, PA, and regular food monitoring and the use of insulin shots.

Minimum Required Effectiveness by Insulin Use and Diabetes Type Subgroups

Participants who did not use insulin required, overall, lower minimum effectiveness to adopt RDM compared with participants who used insulin shots or an insulin pump (did not use insulin and required RDM to be much more effective, 244 of 824 vignette assessments [30%]; used insulin shots, 387 of 1089 [36%]; used an insulin pump, 390 of 935 [42%]) (eFigure 2 in the Supplement). Similar differences were observed between subgroups regarding preventing ophthalmologic complications (participants who did not use insulin required RDM to be much more effective in 266 assessments [32%] compared with 379 [35%] and 362 [39%] for those who used insulin shots and an insulin pump, respectively) (eFigure 3 in the Supplement). Participants' views of the same RDM varied for least half of the 36 vignettes in all participant subgroups.

We found little difference between participants with type 1 and type 2 diabetes in minimum required effectiveness for both outcomes (eFigure 4 and eFigure 5 in the Supplement). Participants' views of the same RDM varied for at least 23 of the 36 vignettes (64%) in all participant subgroups.

Discussion

This large, international study found that many participants would be willing to adopt RDM in their regular diabetes care if it were no more or somewhat more effective in improving health outcomes. However, one-third required that RDM be much more effective than their current diabetes monitoring to adopt it. The minimum effectiveness required to adopt RDM was significantly associated with RDM intrusiveness, and it varied widely among individuals for the same RDM scenario.

These findings are encouraging for the future use of RDM. Two-thirds of participants would adopt RDM if it were somewhat more effective than their current care at improving health outcomes, which may be feasible with existing technologies,[2,7,20,30,31] although there is conflicting evidence.[20,30,32-34] Half of these participants would adopt RDM even if it were no more effective than their current care, potentially motivated by other benefits of RDM (eg, reassurance). Additionally, we found that effectiveness requirements for the same RDM differed substantially among individuals, possibly due to differences in psychosocial characteristics.

RDM that was perceived as more intrusive by participants and RDM that included occasional food monitoring and real-time feedback by another care professional was required to be more effective to be adopted. Thus, patients consider intrusiveness a cost, and they may adapt their requirements for RDM benefits accordingly. Food monitoring and real-time feedback may be considered undesirable because patients worry that they may be judged for their diabetes self-management. Insulin use was significantly associated with both outcomes, possibly because diabetes management is more burdensome for those who use insulin than for those who do not, which could be taken into account in their decision to adopt a burdensome RDM regime. The model for preventing ophthalmologic complications additionally identified worry about future complications and residence in the United States as significant factors. This finding may be confounded by the fact that participants from the United States were younger and more frequently had type 1 diabetes. Worry about future complications corresponds to ophthalmologic complications being a long-term outcome.

A comparison with previous studies is difficult because the benefits patients require to adopt RDM have not been studied. Some randomized clinical trials have reported low adherence to RDM interventions,[15,33,35] whereas others have reported high acceptability.[31,36-38]

RDM holds promise for patients and physicians. First, technological developments could lead to less intrusive monitoring, thereby reducing the magnitude of health benefits required to adopt RDM. Second, patients who require substantial benefits to adopt RDM could benefit from interventions designed to reduce barriers to RDM adoption.

When implementing digital diabetes care, physicians should be aware of the variability in patients' requirements of RDM. Our results show that acceptability of RDM is contingent on how it affects health outcomes that are important to patients and how patients perceive its psychological costs. Therefore, physicians should first discuss the expected efficacy of RDM with patients and codefine treatment goals. Physicians may then use shared decision-making aids, similar to the vignettes used in this study, to help patients select the monitoring modalities that align with the benefits motivating them to adopt RDM and that carry the smallest psychological costs.

Our study focused on RDM adoption. Future studies should examine the association of RDM modalities, intrusiveness, and perceived effectiveness with sustained adherence to RDM. Adherence to digital diabetes technologies tends to decline over time,[39-41] and it may be affected by intrusiveness.[18] Additionally, this study focused on RDM as part of patients' follow-up in the context of health care institutions. Patients' views of using these technologies for self-management without physician involvement may differ. Future studies could also investigate issues around data handling. The balance between privacy protections, trust in private-sector organizations, and increased usability of digital health platforms (eg, by facilitating interoperability) should be examined. Finally, this is a preliminary overview of patients' perceptions of RDM. Experimental studies are needed to test patients' adoption of RDM in a real-world clinical context.

Strengths and Limitations

This study has several strengths. First, this was a large, international study with participants from different countries and health care systems within the Western world. Second, the large sample allowed for precise outcome estimates. Third, the RDM vignettes represent existing sensors and applications. Fourth, the use of vignettes, a methodologically robust tool, allowed us to compare 36 diverse RDM scenarios.

Our study also has some limitations. First, our convenience sample is not representative of the 425 million people with diabetes worldwide. However, a representative sample of this size would have led to small subgroups of populations for whom RDM is highly relevant. Because our aim was to identify characteristics that may affect patients' views of RDM, we recruited a diverse sample in terms of the characteristics whose association with the outcomes we aimed to assess. Second, our sample does not represent the patients who are currently more likely to be offered RDM in clinical settings but rather presents the views of patients with diabetes in general. We decided to explore the perceptions of these patients, for whom use of RDM is likely to be expanded in the future. Third, some characteristics expected to be associated with RDM adoption (eg, frequency of hypoglycemic episodes, current use of digital monitoring tools) may not have been strongly associated with RDM adoption because of limited variability. Results could differ in other populations. Fourth, many study participants were familiar with the use of digital health tools. Therefore, acceptability rates in the overall population of patients with diabetes may be lower than those suggested by our findings. Fifth, the proportional odds assumption did not hold for a subset of factors in the CLMM. Even when the assumption is not met, the CLMM provides a reliable unified average odds for the association between factors and the outcome variable.[42] However, the association of factors to specific levels of the outcome variable may not be reliable.

Conclusions

There is potential for large-scale implementation of RDM in diabetes care. The findings of this study suggest that RDM modalities that are seen as intrusive by patients may lead to greater requirements of health benefits to offset the psychological costs of RDM adoption. The variability in patients' preferences should be considered in the design of minimally disruptive digital health tools as well as by physicians prescribing RDM.

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SUPPLEMENT.

eAppendix 1. Vignette Example
eAppendix 2. Data Collection and Piloting
eAppendix 3. Model Description
eTable 1. Distribution of Minimum Required Effectiveness Ratings per Vignette
eTable 2. Cumulative Link Mixed Model in the Complete-Case Data Set
eFigure 1. Study Flowchart

Part 3: Optimizing DBCIs by leveraging lessons from the COVID-19 pandemic

The impact of the COVID-19 pandemic for patients with chronic conditions has been severe. Other than the direct effect of COVID-19 on people who are vulnerable due to a preexisting chronic condition, the pandemic has affected the provision of routine care to chronically ill patients.[59] For example, a survey with a nationwide representative sample of U.S. adults in June 2020 found that 40% had delayed or avoided medical care because of the pandemic, including screening that could lead to the timely diagnosis of chronic conditions.[60] Modeling studies estimate that delays in screening and treatment for breast and colorectal cancer due to the pandemic could result in 10,000 preventable deaths in the USA.[61]

However, researchers in digital health were quick to seek the silver linings in the pandemic. COVID-19 may have brought us a step closer to the long-awaited digital transformation of care, because, to reduce the spread of the virus, healthcare organizations and professionals had to replace in-person care with remotely-delivered services. Both novel and existing digital tools were used for this purpose. For example, patients with COVID-19 in France were remotely monitored with daily symptom questionnaires through the Covidom app.[62] Tools that were not designed for healthcare, such as commercial messaging and videocall apps, were used to conduct teleconsultations and send patients documents, such as renewed prescriptions.[63]

The sudden acceleration in digital health implementation gave rise to opinion pieces and viewpoints that reimagined the future of care in medical journals.[64–66] These papers describe a hybrid care model in which the care modalities used in the pandemic are maintained after its end and offered in parallel to traditional care. For example, Gunasekeran et al propose the addition of remote monitoring interventions to routine care, led either by care providers or by patients (labelled

"lighthouse model" and "catchment net model", respectively) based on smartphones and the Internet of Things.[64] These interventions strongly resemble the vignettes we used in the first two projects of this thesis.

The hybrid care model can be described as using existing tools and care modalities as versatile puzzle pieces, which can be combined in multiple ways. Each patient-physician dyad must put these pieces together in a way that fits the patient's needs and preferences. Importantly, the alternative care modalities implemented during the pandemic are not limited to sophisticated, high-tech digital tools. For example, telephone consultations were used in place of in-person consultations during the pandemic. Unlike video consultations, telephone consultations do not require familiarity with computers, special equipment (e.g., high-resolution cameras) or broadband internet. Therefore, they may be suitable to reach out to population groups that face difficulties getting to in-person visits (e.g., patients with mobility restrictions, parents of young children, patients in rural areas with poor physician availability without the financial means to travel to the clinic).[67] This has led some physician groups to ask for the temporary regulatory changes motivated by the pandemic (e.g., reimbursement of telephone consultations) to become permanent, so they may continue to provide timely care to their most vulnerable patients.[67]

Some health care organizations and physicians have already established that they will continue to offer remote care after the pandemic,[68] in parallel with in-person care. However, patients have been somewhat absent from this dialogue. Though there have been calls to redesign care with patient voices at the centre,[65] most studies so far have focused on patients' satisfaction with remote care services offered during the pandemic, instead of on their willingness to use these services under "normal circumstances", in the absence of a pandemic.[69,70]

Among the few observational studies that surveyed chronically ill patients who used remote care modalities during the pandemic, to measure their willingness to continue using these modalities after the pandemic, we find primarily single-center studies that report the proportion of their patients that would continue to use remote care modalities. However, these studies do not provide information

regarding how much these modalities should be used, compared to the amount of traditional care use, or in which ways they should be combined with traditional care. Should traditional care remain the default, or should patients be offered the alternative modalities as the principal way to access care? And, if so, are there patient groups or care activities for which replacing traditional care with alternative care modalities is contra-indicated?

The importance of nuance is visible in the results of existing studies. Surveys that ask patients if they are willing to *replace* traditional care with teleconsultations receive different responses than studies asking patients if they wish to continue using *both* care modalities (e.g., 26% of 115 patients in a colorectal surgery clinic stated they would replace traditional care with teleconsultations, but 85% of 172 patients with cancer were willing to continue teleconsultations parallel to traditional care),[71,72] and a survey of 1827 members of the public on Amazon Mechanical Turk, found that participants considered specific care activities done in pre-surgical consultations to be appropriate for teleconsultation but not others (e.g., taking one's medical history and informing them about their treatment options could be completed remotely without affecting quality of care, but physical examination could not).

In our previous work, we identified that the way patients perceive digital care modalities may affect their willingness to adopt them in their care, and that patients' perceptions of digital care modalities are affected by characteristics of the care modalities (e.g., the degree of automation versus involvement of a human caregiver). These characteristics vary widely in the digital modalities implemented in the pandemic. For example, symptom-checkers use fully automated algorithms to make decisions about the patient's care. Contrary, in teleconsultations, technology is used as means of communication that maintains a high degree of patient-physician contact. To design post-pandemic, hybrid care models that are acceptable to patients, we must identify and understand their preferences regarding both how much of their care should be delivered by different digital versus in-person modalities, and the specific care activities that should be performed using digital care modalities.

We addressed these questions by conducting a mixed-methods survey with 1529 chronically ill adults in the ComPaRe cohort. The cohort includes more than 45000 patients with any chronic condition, defined as a condition requiring medical care for at least 6 months, who have volunteered to donate their time to research. Participants in the cohort complete regular questionnaires on their condition, and, additionally, can opt in to receive invitations to participate in additional studies on their condition (24374 cohort participants have opted in to receive invitations).

In this study, we quantified the ideal balance of digital and traditional care modalities. We focused on three modalities: teleconsultations, symptom checkers and remote monitoring. Additionally, we analyzed patients' responses to open-ended questions to develop a comprehensive list of appropriate circumstances in which digital care could replace in person care according to patients, and we composed a description of how chronically ill patients envision the ideal post-pandemic care.

For all questions, participants were asked to think about the total care they received (i.e., patients with multimorbidity were not asked to provide separate responses for each of their chronic conditions). Text responses relevant to characteristics of the chronic illness were coded in the qualitative analysis. For example, in the case of symptom-checkers, qualitative responses indicate that some participants declined the use of this modality because they considered it inappropriate for the specific condition they had (e.g., conditions in which symptoms remain stable over time, symptoms are not easily observed by the patient). These responses were coded as circumstances in which symptom checker use is inappropriate according to patients in our qualitative analysis.

Three findings of this study have direct relevance to the acceptability of DBCIs:

- We identified 67 appropriate and inappropriate circumstances, proposed by patients, for the use of teleconsultations, symptom checkers and remote monitoring versus the traditional-care equivalent. Patients condone the use of digital care modalities for "low-risk" circumstances, where the benefit obtained by traditional care does not justify the effort expected from patients. For example, patients suggested using teleconsultations instead of in-person

consultations for routine follow-up appointments that involve discussion with their physician and prescription renewal, to avoid the "cost" of travel to the clinic. Because behavior change counseling represents such a low-risk care activity, it is likely that patients would condone the development of remote behavior change programs, such as video consultations for smoking cessation and online interactive websites (similar to symptom-checkers) that guide patients to the right DBCI for their needs.

- The 67 appropriate and inappropriate circumstances for the use of digital care modalities proposed by patients concern nuanced characteristics of the patient and the care activity they wish to complete. For example, digital modalities were considered appropriate for patients who had an established relationship with their physician, whose condition was stable, and in some cases, who were still not "experts" in managing their condition and felt they could use the support of digital care modalities. This information cannot be obtained by reading the patient's record, ant there seems to be no simple shortcut for physicians who want to identify which patients would wish to adopt a digital intervention (such as their age or education level). Rather, identifying the right person to prescribe digital care modalities, requires a discussion between the patient and the physician, based on the principles of shared decision-making. This is in line with the findings of our previous studies, which showed heterogeneity among patients' perceptions of the same RDM modalities that was not explained by demographic and illness-related characteristics.
- Finally, participants suggested that their ideal care would include DBCIs that were used during the pandemic, such as online exercise videos or automated reminder systems to support medication adherence. However, these DBCIs were already widely available to consumers before the pandemic, either for a relatively low cost or for free (e.g., free home workout videos hosted on YouTube, web-based dietary interventions offered by the French National Health Insurance provider). We might hypothesize that consumers are either not aware that these products exist, or that they want these products to be offered in a more structured manner, as

part of their care. For example, one of the requisites patients propose for the use of online symptom-checkers is the provision of a mark of "quality assurance", such as a formal approval of the symptom-checker by the Paris University Hospital Trust (AP-HP), to help them tell apart credible symptom-checkers from websites that are not evidence-based and may provide incorrect advice. Patients may have similar concerns about the use of commercially available DBCIs. Another barrier to the use of widely available DBCIs may be that they are not specifically targeting chronically ill patients. Some of the participants who proposed the creation of online resources, such as real-time exercise classes, or informational websites for holistic self-management through healthy behaviors, emphasized the need for these resources to be tailored for patients with a specific chronic condition (e.g., exercise classes developed to help with the symptoms of endometriosis, open only to patients with endometriosis).

In the limitations of this study reported in the article below, we state that the characteristics of the healthcare system could have affected participants' responses. By this statement, we mean that the characteristics of the healthcare system may have affected patients' ideas to improve care after the pandemic, and patients' ideal proportion of alternative care modalities. As an example, some participants proposed foregoing referral letters from family physicians to access some specialists, or remote transmission of such letters without the need for consultation. In a healthcare system where referral letters are not required by the insurance provider to access specialists, this suggestion may not have occurred. The fact that universal health insurance in France reimburses teleconsultations may also affect patients' preference for incorporating teleconsultations in their usual care (e.g., in health care systems where digital care modalities imply out-of-pocket costs to patients, the ideal proportion of digital care modality use may differ).

In the interest of examining the perspective of patients regarding improvements in healthcare before and during the pandemic, we could see the findings of this study in light of a previous study on the same topic, which was carried out before the pandemic and colleted patients' suggestion for the improvement of care.[73] The two studies present commonalities in patients' suggestions (e.g., the

need for centralization of care, with a single entry point for patients such as a coordinating physician or health record, patients' desire to have more information about their care and to receive care adapted to their preferences, desire to reduce burdensome tasks).

The findings of this study are reported in: *Oikonomidi T, Ravaud P, Barger D, Tran V-T.* Preferences for Alternative Care Modalities Among French Adults with Chronic Illness. 2021. *JAMA Network Open (in press).* The online supplement files of the article are presented in Annex 3 of this thesis.

Preferences for Alternative Care Modalities Among French Adults with Chronic Illness

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Key points

Question: What is the correct balance between alternative care modalities, implemented during the pandemic, and traditional care, in the post-pandemic care model?

Findings: This survey of 1529 chronically ill adults found that patients would choose alternative care (i.e., teleconsultations, symptom-checkers, remote monitoring) over the traditional care equivalent for 22 to 52% of their future needs. We identified 67 care activities, patient characteristics, and characteristics of alternative care modalities, for which patients considered it appropriate to replace traditional with alternative care.

Meaning: Alternative care modalities implemented during the pandemic could be used to deliver nearly half of patients' post-pandemic care.

Abstract

Importance: The COVID-19 pandemic led to the implementation of alternative care modalities (e.g., teleconsultations, task-shifting) that will continue to be implemented in parallel to traditional care after the pandemic. The correct balance between alternative and traditional care modalities is unknown.

Objective: To quantify chronically ill patients' ideal post-pandemic balance between alternative and traditional care modalities, and to qualify the circumstances in which patients consider it appropriate to replace traditional care with alternative care.

Design: Mixed-methods survey.

Setting: ComPaRe, a French nationwide e-cohort of adults with chronic conditions who volunteer their time to participate in research projects, from January to February 2021.

Participants: Chronically ill adults in the ComPaRe e-cohort.

Main outcome measures: Participants rated the ideal proportion at which they would use three alternative care modalities instead of the traditional-care equivalent, on a 0-100% scale out of their overall future care: 1) teleconsultations, 2) online symptom-checkers to react to new symptoms, and 3) remote monitoring to adapt treatment outside consultations. We calculated the median ideal proportion of alternative care use. Perceived appropriate circumstances in which each alternative modality could replace traditional care were collected with open-ended questions. Analyses were performed on a weighted dataset representative of chronically ill patients in France.

Results: Of 1529 participants (participation rate 24.9%), 1072 (70.1%) were female, with a mean age of 50.3 ±14.7. Participants would choose teleconsultations for 50.0% of their future consultations (inter-quartile range [IQR] 11.0, 52.0%), online symptom-checkers over

contacting their physician for 22.0% of new symptoms (IQR 2.0, 50.0%), and remote monitoring instead of consultations for 52.3% of their treatment adaptations (IQR 25.4, 85.4%). Participants reported 67 circumstances for which replacing traditional with alternative care modalities was considered appropriate, including 31 care activities (e.g., prescription renewal, addressing acute or minor complaints), 27 patient characteristics (e.g., stable chronic condition, established patient-physician relationship), and 10 required characteristics of the alternative care modalities (e.g., quality assurance).

Conclusions and Relevance: After the pandemic, patients would choose alternative over traditional care for 22 to 52% of the time across different care needs. Participants proposed 67 criteria to guide clinicians in replacing traditional care with alternative care.

Introduction

Half of adults in Western countries have at least one chronic condition and 27% experience multimorbidity.[1] The traditional care model fails to serve the growing population of chronically ill patients, because it is reactive and inflexible: physicians see patients most often only after they become ill, during in-person consultations scheduled at pre-specified intervals.[2] A more appropriate care model for chronically ill patients would seek to prevent health deterioration, support patients outside of consultations,[2] and minimize treatment burden.[3,4]

The COVID-19 pandemic disrupted the traditional care model and forced physicians to implement alternative care modalities, ranging from technology-based remote care to organizational changes. For example, patients in France suffering from COVID-19 were remotely monitored with daily self-reported questionnaires through the Covidom app,[5] and separate hospital areas were dedicated to patients with COVID-19 in Italy.[6] Studies report high patient satisfaction with remote care offered during the pandemic,[7,8] and some health care organizations will continue to offer these care modalities after the pandemic, parallel to traditional care.[11]

This alternative model is a collection of care delivery mechanisms that could be used to improve care for some chronically ill patients, under some circumstances.[12] To leverage the lessons learnt in the pandemic, we must seek patients' perspectives regarding which care alternative care modalities they want to incorporate into their future care and under which circumstances.

To address these questions, we conducted a mixed-methods survey to quantify the ideal balance of alternative and traditional care modalities, and to describe how chronically ill patients envision the ideal post-pandemic care.

Methods

Survey design

We conducted a mixed-methods study using an online questionnaire structured in two parts. First, we asked patients about their views of the ideal balance between three alternative care modalities implemented during the pandemic (teleconsultations, online symptom-checkers, remote monitoring) and traditional care modalities, and about the circumstances in which the use of these alternative care modalities to replace traditional care is considered appropriate. Second, we used open-ended questions to elicit a description of participants' ideal care, inspired by the alternative care implemented during the pandemic. The survey was conducted in French. We present an English translation of the survey in eMethods 1.

The questions were framed according to techniques used in psychotherapy to encourage rich answers from participants.[13] The survey was introduced with a video listing examples of alternative care modalities used in the pandemic. These examples were identified by one author (T.O.) by reviewing systematic reviews on changes in care during the pandemic. The review process is described in eMethods 2. The survey was co-developed with three patients, who participated in semi-structured cognitive interviews. It was pilot tested with four different patients. Survey development is described in eMethods 3. The study protocol was pre-registered on Open Science Framework.[14]

Participants

We recruited a non-probability sample. Participants were adult (≥18 years old) patients with any chronic condition (i.e., any condition requiring healthcare for ≥6 months). They were recruited from ComPaRe,[15] a nationwide e-cohort of 47,000 patients with chronic conditions in France who donate time to participate in research. We invited 5,999 recently active members of the e-cohort (i.e., members that had logged on to their account on the ComPaRe platform in the 6 months prior to January 2021) to participate in the survey via email. ComPaRe was

approved by the Institutional Review Board of Hôtel-Dieu Hospital in France (IRB 0008367). Patients provided informed consent.

Balance between alternative care modalities and traditional care modalities

In this part of the study, patients were asked to indicate the ideal proportion for which they would use three alternative care modalities, replacing the traditional care equivalent: teleconsultations (instead of in-person consultations), online symptom-checkers to identify the right course of action for new symptoms (instead of contacting one's physician), and remote monitoring to adapt treatment outside consultations (instead of sharing monitoring data during consultations) (e.g., "*We would like to know what the ideal balance would be for you, between teleconsultations and in-person consultations. For what proportion of your future consultations would you choose to use teleconsultations?*") Responses used 0-to-100% rating scales. An open-ended question asked patients why they selected the specific proportion.

For each of the 3 questions, we calculated the median proportion at which ideal care would consist of the alternative care modality, and the proportion of participants whose ideal care consists primarily of the alternative modality (i.e., response >50%), primarily of the traditional modality (>5% and ≤50%) and entirely of the traditional modality (≤5%). We assessed the relationship between this proportion and patient characteristics using linear models (age, education, satisfaction with income, multimorbidity, years since diagnosis, previous use of the alternative care modality, Burden of Treatment questionnaire score,[16] and presence of the most frequently reported conditions: endometriosis, diabetes, high blood pressure, asthma, cancer, depression). We used univariate models to identify independent variables to enter in generalized linear models, fit in the complete case dataset. Statistical significance was set at p=0.05. Analyses were conducted using R version 4.0.2.[17]

With the aim of making our findings generalizable to the population of patients with chronic conditions in France, we performed analyses on a weighted dataset with calibration on

margin. Calibration on margin relies on contingency tables of demographic variables to adjust the margins from sample estimates to the margins of the population. To create the margins matrix, we obtained the proportions of people with chronic illness in France by sex, age categories (<24, 25–34, 35–44, 45–54, 55–64, 65–74, >75 years) and education (lower, middle school or equivalent, high school or equivalent, associate's degree, undergraduate or higher education) from the 2017 report of the statistics department of the French public administration DREES (pages 82-85).[18] The Icarus package in R was used to adjust data sample weights iteratively for the aforementioned variables using raking.[19]

Answers to the open-ended questions were analyzed using inductive content analysis.[20] We coded participants' responses with the aim to identify the circumstances in which each alternative care modality were considered an appropriate replacement of traditional care. First, a preliminary coding scheme was developed by T.O. based on analysis of the first 250 responses and the literature.[21] This coding scheme was reviewed by D.B., who used it to independently code 25% of the 250 responses. The authors compared codes and arrived at a consensus for the preliminary coding scheme, which was then used by T.O. to code all remaining responses. New codes were created as needed. D.B. independently coded 20% of the dataset as quality control and the authors resolved discrepancies. When all data were coded, T.O., D.B. and V.T.T. clustered codes that described similar concepts. For additional information, see the living codebook of the study.[14,22] We used a predictive modelling method to estimate the degree of data saturation for each question,[23] to determine the number of additional responses that would have to be analyzed to detect one additional code.

Patients' description of ideal care

Participants answered two open-ended questions which aimed to elicit their perspective regarding ideal care as well as specific suggestions as to how to achieve said ideal. We followed the content analysis process outlined above to code responses for two prespecified variables: 1)

attributes of ideal care, and 2) suggested use of alternative care modalities implemented during the pandemic to achieve ideal care.

Results

Overall, 1,529 individuals participated in the survey from 27 January to 23 February 2021 (24.9% participation rate, eFigure 1, non-respondent characteristics are presented in eTable 1). Participants were mostly female (n=1072, 70.1%) with a mean age (SD) of 50.3 (±14.7) years (Table 1). The most common conditions were endometriosis (19.8%, n=303) and hypertension (17.4%, n=266). Most participants experienced multimorbidity (i.e., ≥2 chronic conditions, n=1062, 69.5%).

Balance between alternative and traditional care modalities

Use of teleconsultations instead of in-person consultations

Participants would use teleconsultations instead of in-person consultations for 50.0% of all their future consultations (interquartile range [IQR] 11.0-52.0%) (Figure 2, eTable 2). Ideally, consultations would be entirely in-person for 20.4% of participants (n=312), primarily in-person for 47.0% (n=719) and primarily remote for 31.2% (n=477). In univariate models, prior teleconsultation use was the only independent variable with a significant association to the outcome (β=18.0, 95% confidence interval [CI]: 11.79 — 24.25, p<0.001, eTable 3).

The circumstances in which teleconsultations were considered appropriate versus inappropriate by patients are presented in Figure 1, Table 2 and eTable 4. Briefly, teleconsultations were considered appropriate for most routine care activities that do not require physical examination (e.g., prescription renewal, discussing check-up results), for patients with mobility or time restrictions due to their condition or life circumstances (e.g., full-time

employment) and who have an established diagnosis, a stable condition, and an established patient-physician relationship.

Use of online symptom-checkers instead of contacting one's physician when new symptoms appear

Participants would use online symptom-checkers instead of contacting their doctor for 22.0% of the times that new symptoms appear (IQR 2.00, 50.0%). Ideally, 36.9% of participants (n=564) would appraise new symptoms entirely by contacting their doctor, 37.5 % (n=574) primarily by contacting their doctor and 23.4% (n=357) primarily by using online symptom-checkers. Two variables with significant association to the outcome were identified: asthma (β=-12.4, 95% CI: -21.86 — -2.83, p=0.011) and endometriosis (β=-8.5, 95% CI -14.62 — -2.27, p=0.007) (eTable 3).

Online symptom-checkers were considered appropriate as decision-aids for patients to decide if an emergency consultation is warranted, for addressing minor, non-urgent ailments, for use at times and places with poor physician availability (e.g., on weekends), as a 'pre-consultation' tool for patients to collect information for the subsequent consultation, and for newly-diagnosed patients without expertise in managing their condition (Figure 2, Table 2 and eTable 4). Symptom-checkers are inappropriate for patients prone to health anxiety and patients with heterogeneous symptoms, atypical of their condition, or symptoms that cannot be reported without help from a physician. Patients' main requirements for appropriate symptom-checker use were quality assurance (e.g., accreditation by a relevant governing body) and supervision of symptom-checker results by a physician.

Use of remote monitoring instead of sharing one's data in consultations to adapt treatment

Participants would use remote monitoring to adapt their treatment outside consultations, instead of in consultations for 52.3% of the time (IQR 25.5, 85.4%). Ideally, sharing monitoring data to adapt one's treatment is done entirely in consultations for 14.9% (n=100 of 669 participants who used health monitoring and were eligible to answer the question), primarily in consultations for 28.7 % (n=192) and primarily remotely for 56.4% (n=377). There was significant, negative association with having cancer (β=27.1, 95% CI: -43.38 — -10.78, p=0.001) and significant, positive associations with level of education (middle school, high school, associate's degree or undergraduate degree and above, reference category: lower education; β=32.0, 95% CI: 12.81—51.26, p=0.001, β=32.0, 95% CI: 13.79—50.27, p<0.001, β=31.5, 95% CI: 12.91—50.01, p<0.001, and β=31.0, 95% CI: 12.74—49.34 , p<0.001), satisfaction with income (comfortable as compared with very difficult situation, β=40.9, 95% CI: 9.93—71.91, p=0.009) and endometriosis (β=16.2, 95% CI: 7.16—25.23, p<0.001) (eTable 3).

Remote monitoring is appropriate for renewing prescriptions, adapting treatment rapidly and assessing if medical help is needed, for patients with unstable conditions, who need or prefer closer follow-up than that offered by traditional care, and whose symptoms do not require physical examination (Figure 3, Table 2 and eTable 4). Patients' main requirement was that monitoring data would be supervised by their physician.

Patients' description of post-pandemic care

We identified 22 attributes of ideal care (eTable 5), including *lean* (i.e., without components that provide no value to patients) (28.2%, n=432) and *responsive t*o patients' needs as opposed to following a one-size-fits-all schedule (13.5%, n=206). Ideal care would be, at least partially, in-person for 13.0% of participants (n=199), and 9.4% (n=143) imagined ideal

care would be the same as pre-pandemic care (e.g., because they were satisfied with their pre-pandemic care, did not consider that improvement was feasible).

Participants reported 113 uses of alternative care modalities to achieve ideal care, outlined below and in eTable 5 and eFigure 2.

Use teleconsultations in the right circumstances

Participants suggested broader use of teleconsultations (38.9%, n=594), particularly for circumstances in which the patient's physical presence at the clinic does not add value to their care (e.g., 18.5%, n=283 suggested doing prescription renewals via teleconsultations). Other than reducing travel, participants explained that teleconsultations provided value because they can be scheduled more quickly than in-person consultations and allow for more regular contact with the physician.

Replace consultations with other communication modalities

Participants suggested that consultations are not the right care modality for many care activities. They proposed renewing prescriptions without consultation (e.g., based on lab test results communicated by e-mail, 2.8%, n=43), and using dynamic care modalities to address issues that arise between consultations (e.g., remote monitoring [4.3%, n=66], brief patient-physician communication via e-mail or "mini-teleconsultations" [8.8%, n=135]).

"Break" the rules for less disruptive care

Some of the suggestions concerned "breaking" care rules. For example, prolonging prescription validity (0.6%, n=10) can reduce consultations and pharmacy visits. Booking consultations via scheduling websites (3.5%, n=54) as opposed to calling the physician offers convenient functions (e.g., alerts when earlier consultations open up). Some participants

suggested that consultations should not be scheduled at pre-specified time intervals but be contingent upon the result of remote screening (0.3%, n=5).

Connect all caregivers in the patients' network

Remote technologies can facilitate communication within the patient's care network, sparing the patient the burden of information sharing between caregivers (e.g., asynchronous communication between the patient's physicians to check medication compatibility, 1.6%, n=25, synchronous, joint teleconsultations with multiple physicians, 0.3%, n=5).

Centralize each patient's care in one record and one physician

A single health record per patient (2.2%, n=34) would be shareable with caregivers, who would consult and update it to avoid information loss. For multimorbid patients, care could be managed by a single caregiver (0.8%, n=13), who could remotely consult specialists on behalf of the patient (1.6%, n=25).

Discussion

In this study, 1,529 patients rated their ideal balance of alternative and traditional care modalities, proposed 67 criteria for the appropriateness of the future use of alternative care modalities, and suggested 113 uses of alternative care modalities to achieve their ideal care. Patients would use alternative care modalities at least some of the time, depending on their health status, constraints and preferences and on the type of care activity they seek to obtain.

Previous studies report that patients want to continue using remote care modalities after the pandemic.[7,8,24] A survey of preferences for pre-operation consultations showed that the perceived appropriateness of teleconsultations varies depending on care activities.[24]

Implications for research and care

Our findings show that we already have at our disposal many of the tools needed to improve care. Deciding which tools should be used for which patient depends on care activity and patient characteristics. Patient-physician dyads can use these characteristics to decide how remote care modalities could fit in the patient's care. Second, some participants in our study envisioned using remote care modalities not to replace traditional care, but to supplement it (e.g., using teleconsultations for more frequent follow-up). This differs from the intended use of these tools as envisioned by developers and clinicians. Third, studies have used fixed patient characteristics to predict the uptake of remote care. Future studies should assess the impact of the time-varying criteria identified in our study on uptake. Fourth, it has been proposed that after the pandemic, care avoidance should be mitigated.[25] The appropriate level of contact with the health care system should be co-defined with patients to ensure that what patients view as sensible care use is not misinterpreted as avoidance. Fifth, patients' preference for alternative care modalities may be affected by cost. The French universal health insurance system reimburses teleconsultations at the same rate as in-person consultations. Novel care modalities would require determining the pricing and reimbursement of these services. Changes in the reimbursement of remote care have already been implemented in the wake of the pandemic.[26] Finally, some of the ideas proposed by participants may be easier to implement in clinical practice than others. For example, prolonging prescription validity could be implemented relatively easily for some medication classes, but not for others (e.g., opioids). Other ideas might require substantial changes in infrastructure (e.g., developing a shared medical record platform).

Strengths and limitations

This is the first study to examine patients' vision of post-pandemic care and identify appropriate uses of alternative care modalities. We analyzed responses from 1,529 patients. The model used to predict data saturation indicates that if we doubled the number of participants in

our study, we would have identified no additional appropriate and inappropriate uses for teleconsultations, two additional uses for symptom-checkers and three for remote monitoring (eFigure 3). Our diverse sample included older and multimorbid patients and was weighted to reflect the general population of chronically ill patients more closely.

This study also has limitations. As ComPaRe is an e-cohort, all participants have internet access. This survey may overestimate patients' access to technology-based care. However, 83% of the French population use the internet.[27] Responses may be affected by characteristics of the French health care system (e.g., universal health insurance). We did not examine the association between ethnicity and willingness to use remote care due to regulatory restrictions regarding the collection of ethnicity data in France.[28] Previous studies have found mixed findings regarding the association between ethnicity and teleconsultation use in general practice during the pandemic.[29] Our results may not be generalizable to non-francophone immigrants. Despite weighting, our sample is not perfectly representative of the general population of chronically ill patients regarding the prevalence of specific conditions (e.g., endometriosis). This may limit the generalizability of our findings. Study respondents were more likely to experience multimorbidity and hypertension, and less likely to have endometriosis than non-responders. Finally, some suggestions identified in the qualitative analysis were reported by a small number of participants.

Conclusion

In this study, we presented the views of 1,529 patients regarding the appropriate use of alternative care modalities inspired from the pandemic and the right balance between alternative and traditional care modalities. These findings provide a roadmap for redesigning care in collaboration with patients after the pandemic.

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Access to Data: TO had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Author contributions: TO conceived the study, designed the survey, collected and analyzed data and wrote the manuscript. VTT conceived the study, designed the survey, analyzed data and reviewed/edited the manuscript and acts as guarantor. DB provided critical feedback to the protocol, analyzed data and reviewed/edited the manuscript. PR conceived the study and reviewed/edited the manuscript. All authors approved the final draft.

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Data availability: The anonymized dataset is available upon reasonable request to the corresponding author. The study protocol and the living codebook are available on Open Science Framework (https://osf.io/v3kd7/?view_only=a5b10a9f921547e09d40b791b8565373).

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Table 1. Participant characteristics in the unweighted and weighted sample.[a]

Participant characteristics, No (%)	Unweighted sample (n=1529)	Weighted sample (n=1529)
Men	457 (29.9)	721 (47.2)
Age (y), mean ± SD	50.28 ±14.73	55.25 ± 16.97
Education		
Lower education	44 (2.9)	149 (9.7)
Middle school or equivalent	148 (9.7)	862 (56.4)
High school or equivalent	226 (14.8)	211 (13.8)
Associate's degree	323 (21.1)	134 (8.8)
Undergraduate or graduate degree	788 (51.5)	173 (11.3)
Feeling about household income	**n=1389**	**n=1384**
Finding it very difficult on present income	36 (2.4)	35 (2.3)
Finding it difficult on present income	145 (9.5)	172 (11.2)
Coping on present income	695 (45.5)	809 (52.9)
Living comfortably on present income	513 (33.6)	368 (24.1)
Number of chronic conditions, median (interquartile range [IQR])	2.00 [1.00, 4.00]	2.00 [1.00, 4.00]
Multimorbidity	1062 (69.5)	1057 (69.1)
Self-reported diagnosis [b]		
Endometriosis	303 (19.8)	180 (11.8)
High blood pressure	266 (17.4)	307 (20.1)
Depression	149 (9.7)	151 (9.9)
Diabetes	148 (9.7)	166 (10.9)
Asthma	130 (8.5)	105 (6.9)
Cancer	114 (7.5)	146 (9.5)
Years since first diagnosis, median [IQR]	16.00 [6.00, 28.00]	17.00 [7.00, 29.00]
Total score, Treatment Burden Questionnaire, median [IQR] [c]	55.00 [29.00, 80.00]	51.00 [25.00, 80.00]
Has used teleconsultations [c]	**n=1505**	**n=1508**
Yes	792 (51.8)	741 (48.5)
Has used online symptom-checkers [c]	**n=1498**	**n=1495**
Yes	258 (16.9)	235 (15.4)
Has used remote monitoring [c, d]	**n=636**	**n=669**
Yes	198 (12.9)	215 (14.0)

[a] Weighted data were obtained after calibration on margins for sex, age and educational level by using data from a national census describing the French population with chronic conditions.

[b] Non-exhaustive list. Some participants reported multiple conditions

[c] Missing data, n=127.

[d] Only participants who use monitoring to manage their condition were eligible to answer this question (n=636 in the unweighted dataset and n=669 in the weighted dataset).

Table 2. The 15 most frequent suggestions for the appropriate and inappropriate uses of alternative care modalities, as a replacement of the traditional care equivalent, as perceived by 1,529 chronically ill patients. [a]

Appropriate and inappropriate uses	**Quotes**
Care activities	
Appropriate for prescription renewal	For a simple consultation to renew a prescription, teleconsultations are a great tool. But for more complex problems, being face-to-face with our physician is better. (woman, 39 years old, teleconsultation)
Appropriate to rapidly appraise urgency	It could be practical to know quickly if there is a reason to worry or not (woman, 24 years old, online symptom checker) Yes, if it was a chronic condition for which the follow-up is already in place and if the symptoms were not too worrisome, [the online symptom checker] allows us to avoid a useless consultation and to feel reassured when symptoms appear (woman, 60 years old, online symptom checker)
Appropriate for adapting treatment	It's reassuring both for the patient and the physician (for example, [it shows] if the medication is well-tolerated and not rejected [by the patient] and other incidents) (man, 84 years old, remote monitoring)
Appropriate for routine follow-up consultations	The essence of my contacts with my specialists are the discussion -not the exams (exams such as blood tests and radiology are done separately). Most of the time, physicians just read the exam results while I'm there, then we have a brief discussion, which could absolutely be done by teleconsultation. Being there in person does not add much value. (man, 58 years old, teleconsultation)
Appropriate when other types of care are unavailable (e.g., on the weekend or at night)	I'd first use a symptom checker before calling my doctor, if one for diseases other than covid was available, because experiencing pain often makes us panic and we need to calm down, so any tool that can help us rationalize and re-contextualize the pain is good, because our professional caregivers are not always available and nights can feel long sometimes, so I'd take anything that can help (woman, 36 years old, online symptom checker)
Appropriate for urgent needs	Teleconsultations could be used in specific, urgent cases... which I try to avoid experiencing. [I prefer] in-person consultations for all normal occasions, because the personal contact is part of care for me (woman, 41 years old, teleconsultation)

Inappropriate for urgent needs	In a situation where I do not feel like I am at major risk, I'd be satisfied with such a tool that can quickly orientate me towards the right care modality. But if I have symptoms that feel critical, I would opt for a real consultation because I know that it's impossible to replace a global appraisal by a good doctor with a list of non-exhaustive, quick questions from this digital tool. If the tool was perfectly exhaustive though, I'd consult it much more often. (woman, 36 years old, online symptom checker)
Inappropriate for physical examinations [a]	Every other consultation should be done in person for the patient-physician relationship and to measure [patients'] blood pressure, weight, blood tests etc (woman, 75 years old, teleconsultation)
Patient characteristic	
Appropriate for patients requiring closer follow-up than that offered by traditional care	I got to evaluate this tool through the example of a young pregnant woman in my family. It seems to work very well for those who need to follow their data more closely. This is not my case. The occasional medical tests suffice (woman, 65 years old, remote monitoring)
Appropriate for patients with restricted mobility [b]	No need to wait seated on hard, uncomfortable chairs. Sitting down can be very painful for me, being home where it's warm and quiet is much more pleasant. I have managed to keep my appointments even when I was having a crisis, I'd have cancelled these appointments if I had to get to the clinic, because transport + waiting on the chair would have been too difficult and it would have taken me time to recover afterwards. (woman, 42 years old, teleconsultation)
Appropriate for medical deserts	The reference centre where I'm followed up for my endometriosis is more than 100 kilometers from my place (woman, 36 years old, teleconsultation)
Appropriate for stable condition	When there is nothing new, no change, teleconsultations are largely sufficient and they save us time (woman, 54 years old, teleconsultation)
Appropriate for conditions the symptoms of which can be observed and reported by patients	I may not notice some symptoms that would alert a professional to an urgent issue. This has already happened in the past, and it could have been fatal. (woman, 31 years old, online symptom checker)
Inappropriate for patients prone to anxiety regarding their health [c]	It's a great tool for well-informed patients, but it could be harmful for those who pay too much attention to themselves or are hypochondriacs. (man, 57 years old, online symptom checker)
Care modality characteristics	

Appropriate if the tool is supervised by a physician [d]	[I would use symptom-checkers] only if my doctor sent a notification in case of symptoms or behaviors that warrant one (man, 35 years old, online symptom checker)

[a] Patients' appraisal of the need for physical exams is subjective.

[b] Refers to restrictions due to a health condition. Includes pain, fatigue.

[c] Patients may overestimate the gravity of their symptoms.

[d] Supervision refers to the physician reviewing the results of the symptom-checker, either as needed or irrespective of the symptom-checker's result, and to the need for physicians to commit to view remote monitoring data.

Figures

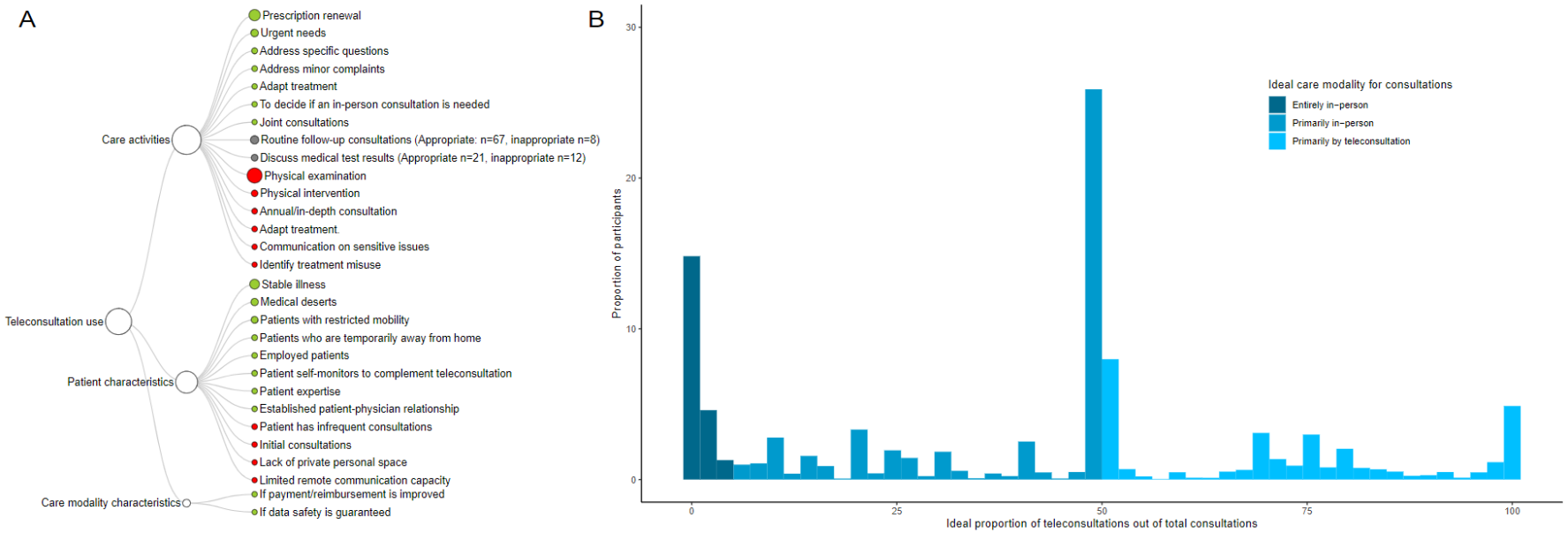

Figure 1. Ideal proportion and perceived appropriate uses of teleconsultations.

Panel A presents the circumstances in which participants consider teleconsultations to be an appropriate (green nodes) or inappropriate (red nodes) replacement for in-person consultations. The grey nodes indicate circumstances that were reported both as appropriate and inappropriate by different study participants. The number of participants with conflicting opinions is reported in the parenthesis. Panel B presents the proportion of participants that would, ideally, conduct their future consultations entirely in person (dark blue bars, ideal proportion of teleconsultations 0 to 5%),

primarily in person (blue bars, ideal proportion of teleconsultations 6 to 50%) or primarily by teleconsultation (light blue bars, ideal proportion of teleconsultations >50%).

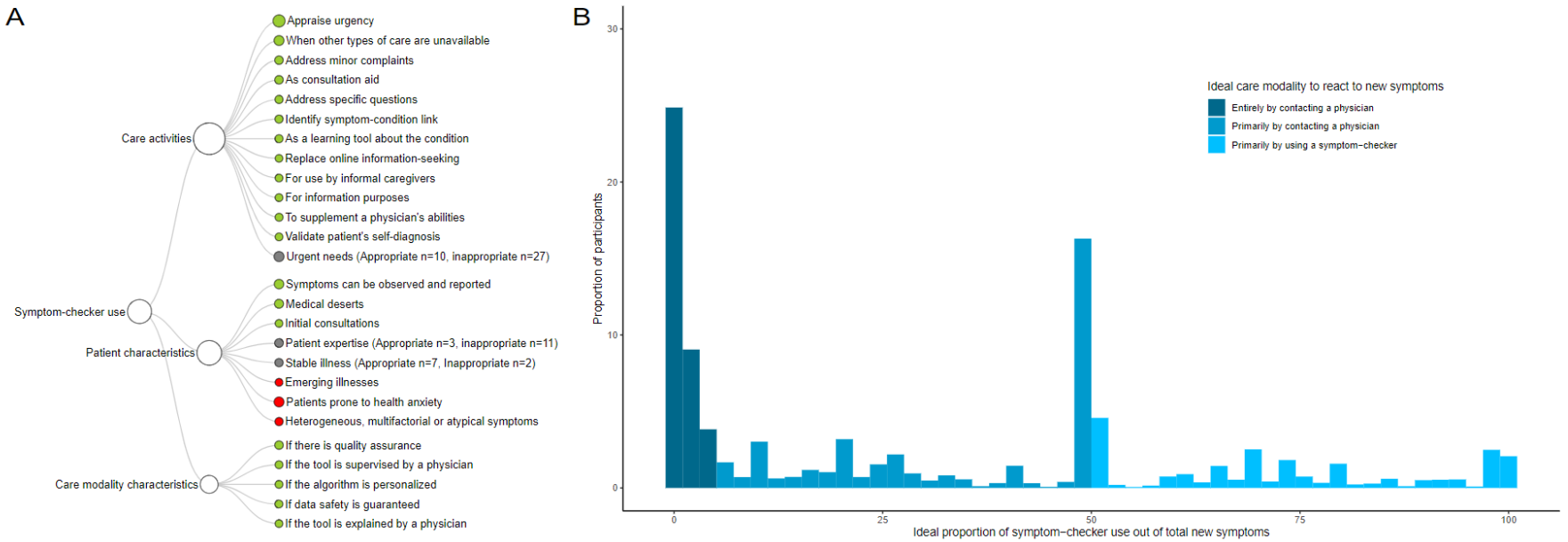

Figure 2. Ideal proportion and perceived appropriate uses of online symptom-checker use.

Panel A presents the circumstances in which participants consider using online symptom-checkers to identify the right course of action when new symptoms appear, to be an appropriate (green nodes) or inappropriate (red nodes) replacement for contacting their physician. The grey nodes indicate circumstances that were reported both as appropriate and inappropriate, by different study participants. For these nodes, the number of participants with conflicting opinions is reported in the parenthesis. Panel B presents the proportion of participants that would, ideally, react to the appearance of new symptoms in the future entirely by contacting a physician (dark blue bars, ideal proportion of symptom-checker use 0 to 5%),

primarily by contacting a physician (blue bars, ideal proportion of symptom-checker use 6 to 50%) or primarily by using symptom-checkers (light blue bars, ideal proportion of symptom-checker use >50%).

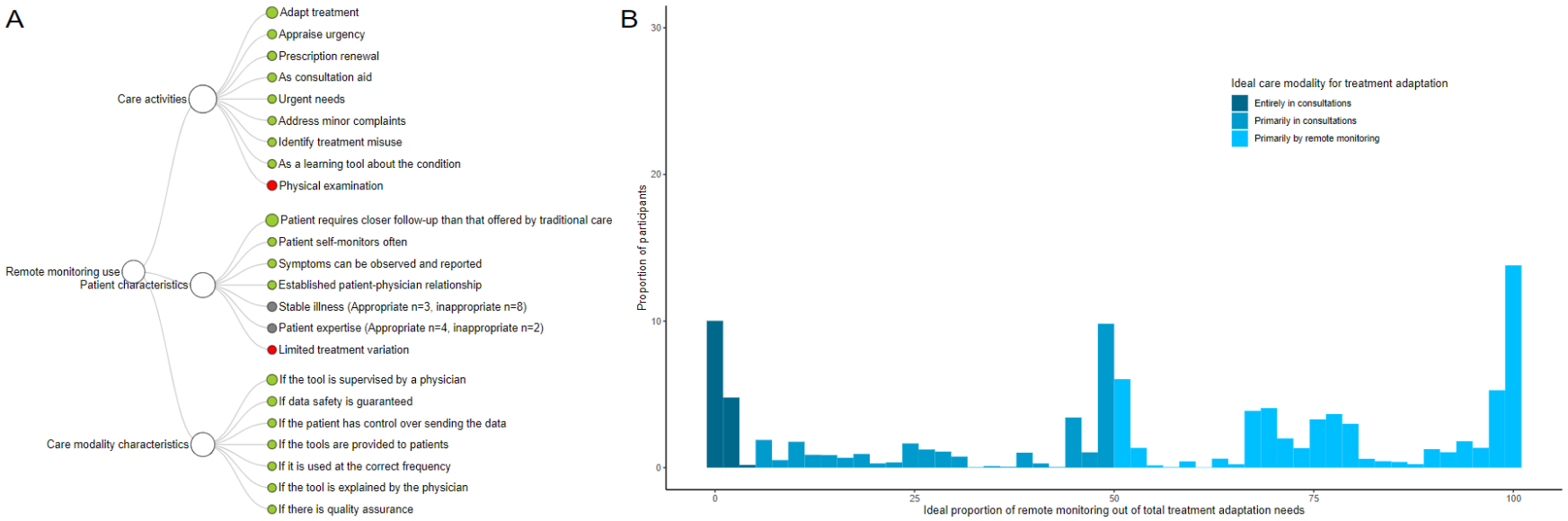

Figure 3. Ideal proportion and perceived appropriate uses of remote monitoring.

Panel A presents the circumstances in which participants consider remote monitoring for treatment adaptation outside consultations to be an appropriate (green nodes) or inappropriate (red nodes) replacement for adapting their treatment after revising monitoring data in consultations. The grey nodes indicate circumstances that were reported both as appropriate and inappropriate, by different study participants. For these nodes, the number of participants with conflicting opinions is reported in the parenthesis. Panel B presents the proportion of participants that would, ideally, have their treatment adapted entirely in consultations (dark blue bars, ideal proportion of remote monitoring 0 to 5%), primarily in consultations

(blue bars, ideal proportion of remote monitoring 6 to 50%) or primarily outside consultations by using remote monitoring (light blue bars, ideal proportion of remote monitoring >50%).

Discussion

In this thesis, we collected and presented information that might help healthcare professionals understand how we can design and prescribe DBCIs that patients are willing to adopt. We approached this question with the understanding that personalized DBCIs can be particularly intrusive because of the large amount of data required for intervention adaptation and the "just-in-time" character of this interventions: interventions that are embedded in real-life contexts will, inevitably, interrupt the flow of real life. We explored patients' perceptions of intrusiveness and willingness to adopt different components of DBCIs, focusing on monitoring and feedback modalities, two of the most common BCTs found in behavioral interventions. Finally, we explored patients' ideal post-pandemic balance of digital and traditional care and we identified the appropriate circumstances in which digital care could replace traditional care, according to patients.

In the following sections, we will explore the implications of this thesis for research, health policy, and the care of chronically ill patients.

Rethink behavior change interventions

The current way of offering patients behavior change interventions is at odds with patient-centered care.

Similar to many non-digital behavior change interventions, DBCIs tend to follow a rigid, pre-specified format: each intervention includes a number of BCTs, that the patient is required to enact in a specific manner (e.g., self-monitor dietary behavior and of weight, daily, for the entirety of the intervention period, and receive feedback on dietary behavior once a week, by a dietician, by phone call). When patients visit their physician, they receive a recommendation for one behavior change intervention (at most), instead of being given a list of DBCIs they could choose from. If the proposed

intervention does not fit the needs, preferences or capacity of the patient, their only alternative option is often to receive no behavioral support.

Our findings show that patients have strong views and preferences about specific BCTs and BCT delivery modalities, which indicates the need for a more flexible approach to offering behavior change interventions. For example, we could envision an à la carte system, in which patients can mix and match from a menu of available BCTs and delivery modalities, such as intervention duration, automated versus human-driven delivery, in-person versus remote delivery. This could be similar to the business model adopted widely by gyms, in which a single subscription gives the client access to different exercise classes and machines. Coaches are available to explain what each class entails and help clients select the best program for their needs and preferences, but ultimately, the client takes the lead.

To implement flexible behavior change care, we need to develop a menu of tools and DBCIs that fit different patient profiles. Many of these tools have already been developed in the private sector, but are not recommended or prescribed to patients. The barriers that prevent private-sector innovation uptake, such as lack of safety and efficacy vetting, need to be addressed. New tools can be developed based on patients' own vision for the hybrid care model. For example, inspired by a participant's response to our third study, we could imagine "bite-sized" teleconsultations (e.g., 5-minute phone calls, asynchronous chat), in which the patient initiates contact with their regular behavioral counselor, in near real-time when they need support. Finally, flexible behavior change care requires a culture shift in health psychology: we must part ways with behaviorism's tendency to exercise control over its *subjects*, and accept patients' need for ownership of their behavior change journey.

Implications for research

Take into account the opinion of large, diverse patient groups in DBCI design

In a previous review of mobile health (mHealth) behavior-change interventions assessed in RCTs, we found that information about the basis of intervention design (e.g., behavioral theory, previous research, consultation with clinicians or patients) was specified only in half of the included reports.[74] When the reported basis for intervention design included patient involvement, the methodology was most commonly focus groups, with a small number of patients who were asked for feedback when a prototype of the intervention had already been drafted. We believe that it is possible to involve a greater number of patients, with diverse characteristics (within the target population of the intervention), at an earlier stage of intervention design.

In all three of our studies, patients read short descriptions of key components of digital interventions, and they provided rich, nuanced, free-text feedback about the potential barriers of incorporating the intervention in their lives, and the life contexts for which they consider using the intervention to be appropriate. This approach could be tested as a method of DBCI design. Vignettes could be used to propose different versions of a DBCI (e.g., with different BCTs, with more versus fewer monitored variables, different feedback frequencies) to a group of patients, to elicit quantitative and qualitative feedback that can guide intervention developers in finalizing the DBCI design, before a prototype has been built. Multimorbid, older, or employed patients, who may not be able to participate in in-person focus groups, may be willing to give feedback for DBCI design in short, asynchronous online studies. This approach, which has already been used in product design (e.g., discrete choice experiments), could help developers design DBCIs in which personalization offers better cost-benefit balance to users.

Measure patient experience with DBCIs as their use in routine care proliferates

Our studies focused on patients' stated, as opposed to revealed, preference. Future studies should examine the association between intrusiveness and willingness to adopt DBCIs in real-life conditions. Intrusiveness and its relationship to DBCI adherence should be studied longitudinally,

given that perceptions of intrusiveness could change as the patient develops a habit of using the device.

As DBCI use in care increases, existing means of data collection (e.g., routine data collection during or after consultations, data collection in existing research cohorts) could be used to collect information on patients' experience of using DBCIs. Attention should be accorded to examining how using DBCIs affects vulnerable patient groups. For example, we found that some patients worry about self-monitoring at work, because being spotted self-monitoring by their employer would reveal that they have a chronic condition, and potentially affect their professional prospects. This concern may be more pertinent for specific professions in which employees are under close scrutiny and could face precarity if fired. Vulnerability to the impact of DBCIs may also be due to multimorbidity. For example, patients with diabetes and eating disorders could experience giving their physician access to their nutrition data as particularly anxiety-inducing, which may, in turn exacerbate symptoms of the eating disorder.

Beyond intrusiveness, there are other perceptions that may affect patients' uptake of DBCIs that could be routinely collected as their use increases. A review of 58 trials assessing interventions using biological monitoring devices identified 76 such perceptions, including aspects of the impact of these devices on patients' lives.[75] This study also found that only 26 of the 58 included trials collected data on any patient perceptions toward the intervention. These 26 studies used heterogeneous measures (i.e., different questionnaires, items measuring the general satisfaction or acceptability of the device), which led to some patient perceptions being assessed in very few trials (e.g., only 3 trials assessed patients' perception of data handling and privacy protection).

Identifying which patient perceptions are most impactful on patients' lives, and most likely to affect adoption and adherence, and standardizing the way these perceptions are measured, could help future researchers focus on measuring the patient perceptions that matter most, and increase homogeneity to facilitate evidence synthesis.

Measure the burden of treatment associated with DBCI use

Findings from the qualitative analysis of our first study imply that the digital, remote delivery of healthcare has implications for the treatment burden patients experience. As mentioned above, some digital interventions could reduce some types of treatment burden experienced by patients (e.g., by reducing tasks associated with measuring and dispensing medication manually). However, digital interventions may increase other types of burden.

Taking the Treatment Burden Questionnaire (TBQ) as an example, we can identify two items that would be impacted by the relocalization of healthcare from the clinic into the private sphere: being reminded of one's health condition, and having one's healthcare impact their relationship with others (e.g., due to having to perform healthcare tasks in public). Furthermore, the way in which burden is measured may require further specification, to include aspects of digital healthcare. For example, the items included in the TBQ do not explicitly refer to the burden of treatment associated with patient-physician communication outside the traditional consultation format. In the case of DBCIs (such as the vignettes assessed in our first two studies), a large proportion of patient-physician communication would be delivered remotely, outside consultations, via rea-time or asynchronous feedback messages. Being monitored by a healthcare professional is similarly not explicitly addressed in the TBQ (the relevant item refers to self-monitoring; however, some digital remote monitoring modalities may not actually require that the user self-monitors, such as wearable sensors that collect and transmit data to the patient's physician without action being required from the patient).

Co-design research studies with patients

To design the surveys used in this thesis, we consulted patients' opinion of an initial set of questions that we developed, by using cognitive interviewing. Cognitive interviewing is a structured process used in the design and testing of questionnaires, that involves techniques to elicit the reflective reaction of the participants to the questions, such as think-aloud questionnaire completion. The addition of open-ended questions that provided rich qualitative data (e.g., the questions on the

appropriate and inappropriate uses of digital care modalities in the third study -which can be applied to other research questions such as appropriate uses of specific BCTs) came from patients' suggestions in cognitive interviews. Patient involvement in survey design through structured processes such as cognitive interviewing can improve the study and provide findings that would have otherwise been missed. Surveys could also include new means of information presentation. For example, by using a short video to communicate the idea of alternative, remote care modalities used in the pandemic to participants in our third study, we avoided creating a "text-heavy" survey. Patients who pilot-tested the survey experienced the use of video as interesting and attention-grabbing

Further research may be required regarding the effect of survey co-design approach on the final survey. Other than cognitive interviewing, there are several approaches to involve participants in survey development, such as group debriefing or behavior coding. Although pros and cons of each method have been reported by researchers,[76] to our knowledge, there is no direct comparison of how using each method affects the final structure of the survey (e.g, question order, exclusion of questions). Alongside the effect of co-design approach to survey structure, the effect of using different numbers of participants in co-design should be studied.

Develop shared decision-making aids for digital health interventions

The first two studies of this thesis showed there is large variability in patients' perceptions and willingness to adopt the same DBCI, which is not explained by demographic and illness-related characteristics. The third study showed that patients use nuanced criteria to identify the care activities and patient groups for which digital care can replace traditional care.

DBCI prescribing requires identifying for which patients and which care activities the DBCI may be used, without reducing the quality of care. The factors that patients seem to consider relevant in making this decision are not stable over time (e.g., the care activities a patient needs to complete change quickly, and may render digital care inappropriate), and not easily elicited from routinely collected data (e.g., having a trusting patient-physician relationship). This leads us to assume that

identifying the right patient to prescribe DBCIs to, at the right time in their care, can only be achieved by respectful discussion between the patient and the physician in which the patient's status, needs and preferences for digital care are explored. Because of the many factors associated with the appropriateness of digital care implementation, decision-aid tools may be needed to structure the patient-physician discussion by listing the factors that are important in personalizing DBCI prescription.

Applying shared decision-making in digital care will become particularly relevant as the DBCIs that might be prescribed for the same purpose proliferate (e.g., multiple effective and safe smoking cessation apps become available). This is already the case in glucose monitoring, where patients may be prescribed different continuous glucose monitoring systems. At that time, patients will need support to choose the DBCI that best fits their lifestyle and that they can more easily adhere to. This support could take the form of cards, similar to those used for shared decision-making in diabetes care, which present key characteristics of the DBCIs (e.g., duration and frequency of active monitoring, presence of specific BCTs such as being monitored by a caregiver versus self-monitoring).

One challenge that may arise in the use of decision making for digital interventions, is the fact that digital hardware and software can be subject to rapid modification. Unlike a medication in the form of pills, with relatively stable and known composition, shape, size and side-effects, the components that make a digital intervention intrusive (e.g., parameters of data storage, users' ability to deactivate certain alerts) are relatively easy to modify for developers. Future studies should examine how the fluidity of digital therapeutics can be accommodated in shared decision-making tools and how frequently the initial decision to use a digital therapeutic should be renegotiated in the patient-physician dyad.

Implications for health policy

lly distributed resource

Previous sociological work has criticized digital health interventions (particularly interventions that aim to measure and change behavior) for placing the responsibility to avoid disease solely on the individual. Focusing on individuals' power to avoid disease by making better "lifestyle choices", clashes with the fact that unhealthy behaviors can partly be explained by financial and social determinants that are often outside the control of the individual (e.g., stress related to job insecurity, financial accessibility of hyper-processed foods compared to healthier foods).[42,77,78]

Indeed, addressing the social determinants of health behavior requires economic and policy interventions at population and community level. However, population- and individual-level interventions are not mutually exclusive.[79] Health care professionals work with individual patients and require safe, effective, and low-burden interventions they can offer to support individuals in living healthier lives.[77] To achieve that, DBCI scale-up needs to be framed by policy that supports individuals whose lack of opportunity to change their behavior (e.g., inability to afford the cost and time of cooking healthy meals) cannot be "fixed" by a DBCI.

In addition to such policies, we need regulatory frameworks that support the scale-up of DBCIs. For example, some patient concerns identified in our first study can be addressed by establishing and continuously reinforcing privacy-protecting regulations that limit third-party access to monitoring data collected by DBCIs and regulate secondary data uses, such as targeted advertising. Existing regulations provide some protections (e.g., the European Union Data Privacy Regulation, GDPR), but compliance by the private industry is not assured.[80]

Implications for care

Use automated DBCIs to change behaviors that carry stigma

A common concern about AI-driven care is that it may erode the patient-physician relationship.[81] However, participants in our first study reported worry about receiving judgmental

feedback from their caregivers, if they were to share data on their glucose levels and eating behaviors. Food, in particular, was treated as a sensitive subject, and some participant brought up past experiences of health care professionals' hostile communication on the topic of food (with one participant labelling health care professionals "the food police"). This is not specific to digitally-mediated interventions. Previous studies have documented that patients with diabetes often avoid discussing self-care behaviors because of shame and fear of being judged about their nutrition and weight.[82] We propose that the use of automated personalized DBCIs, in which humans neither access the monitored data nor provide feedback, can be beneficial for morally-stigmatized behaviors such as nutrition, alcohol use or sexual behaviors. In this context, AI could be perceived as a neutral, "safe" intervention-provider. A requisite for the use of AI with stigmatized behaviors is that AI-generated communication remains non-violent. For example, feedback messages produced by algorithms should be programmed to include non-judgmental, positive language, and avoid fear-based messages. This is not a question of efficacy of fear-based messages in changing health behaviors (though recent studies do show that fear-based messages have to be combined with empowering messages to work),[83] but a question of designing AI-based interventions that correspond to patients' motivation for selecting AI-based interventions over the human-delivered equivalent. Because algorithms are known to inherit the biases of their human creators,[84] automated DBCIs require mindful design.

Establish trusting relationships between patients and healthcare professionals

Despite the many characteristics that set DBCIs apart from traditional interventions, they are yet another care modality that is implemented in the context of the patient's treatment. Especially in the case of patients with multimorbidity, the DBCI and its user are situated inside the network of many pharmacologic and non-pharmacologic treatments, and several formal and informal caregivers. Therefore, the implementation of DBCIs will inevitably be affected by the pre-existing human relationships in the patient's care network.

Although discussing the ways in which the relationship between patients and their caregivers might become more respectful and egalitarian is outside the scope of this thesis, our findings suggest that many patients feel their current relationships with the caregivers do not provide the necessary trusting and positive context in which DBCIs could be successfully implemented. This was suggested by patients in the qualitative analysis of our first study, in which some of the sources of intrusiveness that patients identified were associated with negative patient-physician relationships, and with the lower hierarchal position of patients compared to professional caregivers in the patient-physician relationship (e.g., worry about judgment, fear of having their control over their health taken away), and in our third study, in which having an established, trusting patient-physician relationship was proposed as a necessary condition for the safe and effective implementation of digital care.

Limitations

All studies in this thesis were carried out via the use of online questionnaires. We can therefore assume that all participants had the knowledge and equipment to access the internet. These surveys could not have reached patients who did not have the means to use technology-based care, or who fundamentally oppose the use of digital technologies. Therefore, our findings are not applicable to these population groups. Had these population groups been included in our work, we may have found more negative perceptions of DBCIs (e.g., higher intrusiveness ratings and lower willingness to adopt digital health interventions). However, our recruitment strategy had several advantages. First, patients that already have access to and familiarity with digital technologies are likely to be the first patients to be offered digital interventions in routine care, because they do not require particular training or support in using digital technologies. Additionally, people who fundamentally oppose or have no access to digital devices represent a relatively small proportion of the population. For example, 83% of the French population use the internet.[17] Finally, the use of online surveys helped us to reach a large number of participants in very short time (recruitment for each survey lasted a few weeks to a few months) with minimal cost, even when pandemic-related restrictions that would have made in-

person recruitment difficult were in place. Had we used exclusively in-person recruitment, some of the analyses we performed (e.g., a comparison of intrusiveness ratings between patients from different countries) would have been impossible. However, internet access is an unequally distributed resource, with the least developed countries having much lower coverage of internet access compared to wealthier nations, and even within nations or geographical regions, access to the internet may be lower in rural than in urban areas, and for women than for men.[85] In this aspect, digital care could fail to reach the people who need it the most, such as residents of remote areas, and it could exacerbate existing inequalities.[85]

There are several barriers that may prohibit patients from accessing digital care oher than internet access. For example, the absence of stable housing may be a barrier to the use of monitoring systems that require a transmission device (i.e., a device which is placed in the patient's home, to capture data from monitoring devices and send them to a centralized data storage structure for caregivers to examine), and digital literacy can affect patients self-efficacy regarding their capability to use digital care.[52,86] Finally, although the French universal health insurance system already reimburses some types of digital care, in other health care systems the cost of accessing digital care can be prohibiting. These factors are not stable over time. For example, digital literacy can decline if patients do not continuously have access to opportunities to engage with new types of technology, and a patient who can make the initial investment in digital care may be unable to consistently afford consumables (e.g., single-use sensors for continuous glucose monitoring devices), or to afford to upgrade their hardware and software (e.g., smartphone) when the digital health intervention becomes incompatible with older devices or operating systems.[52] Our findings may not be generalizable to patients who face these barriers to accessing digital care.

Associated to the issue of representativeness and generalizability, is the fact that this thesis drew findings from two studies: one conducted with an international sample, and one conducted with French participants. This raises the question of the different preparedness of health care systems to accommodate digital care. To this point, the pandemic may have demonstrated that, when necessary,

the implementation of digital interventions becomes feasible. To the extent that the parameters associated with being a patient in different countries (with different insurance systems, cultural attitudes, etc.) affect patients' willingness to adopt digital care, we propose that these parameters could and should be taken into account when the use of digital care modalities is discussed between patients and physicians through shared decision-making.

We explored intrusiveness and willingness to adopt digital health interventions using stated preference measures. The main advantage of choosing this method, is that it allowed us to compare patients' views of many different digital components (i.e., monitoring tools, feedback loops etc.). This would not have been feasible using revealed preference methods (e.g., replicating our vignette design would require a factorial RCT design with 36 arms). As discussed above, experimental, longitudinal studies are needed to test our findings in real-life care circumstances.

Had we chosen not to use surveys as the data collection tool in this thesis, we could have used interviews, focus groups or observation to study patient perceptions of digital care. For example, we could have conducted interviews or focus groups, potentially using images or videos to demonstrate the functions of different DBCIs to participants. Interviews may have provided a more in-depth understanding of intrusiveness, primarily because of their iterative nature (i.e., depending on the insights from the first few interviews, the interview guide can be adapted to subsequently focus on identified themes of interest to the researcher). However, this would have limited the sample size drastically, due to the workload involved in the conduct and analysis of interviews, and it may have required more intensive recruitment, because of the different amount of effort required for interview participation compared with survey participation. It would also have limited eligibility to anglophone participants, because the researcher was not fluent in French. In the case of our first study, we could have opted to study patients who have already used DBCIs, using interviews or observation (i.e., non-participative observation of DBCI users, as they interact with the DBCI in their daily life). However, this would have limited us to existing interventions, with uncontrolled heterogeneity. Vignettes allowed us to vary specific factors of the DBCI while keeping other factors fixed, to study the effect

of each factor level, and to describe RDM with the desired behavioral and biological monitoring components. Identifying a large number of patients using complex RDM in their usual care was not feasible.

Finally, our work did not examine the association between patients' perceptions of digital health and the quality of their relationship with their physician. Some of our qualitative findings point to a potential effect of the patient-physician relationship on patients' attitudes towards digital health. For example, in our third study, we identified that having an established patient-physician relationship was considered as a requisite for the appropriate use of teleconsultations and remote monitoring by some participants. In our first study, participants expressed concern about their caregivers' reactions (e.g., fear of being judged for their glucose control or their dietary habits, if they were to give their caregivers access to their real-time data). It is likely that the use of some DBCIs is experienced differently by patients in trusting, respectful patient-physician relationships, compared to patients who are fearful of hostile, judgmental and non-empathetic reactions from their physician.

Conclusion

Healthcare professionals and researchers aspire to develop patient-centric care that fits in patients' lives without creating disruption. However, there is still a long way to go to achieve minimally disruptive DBCIs that patients will be both capable and willing to adopt. There are multiple reasons for this: in the case of personalized digital interventions, the study of how novel treatment delivery mechanisms transform the way patients experience care and their role in it is still in its infancy. In the case of behavior change interventions, further research is needed to understand patients' perceptions and acceptability of the many different BCTs, and develop ways to ease the psychological burden associated with changing behaviors that carry connotations of morality, stigma, and shame. For example, the intrusiveness and treatment burden associated with behavioral interventions aiming to change sexual behavior, tobacco or alcohol use, has never been systematically studied.

In the future, we can imagine kind and careful behavioral care that is based on shared decision-making, in which each patient is given the DBCI with the right components and frequency, based on their values, lifestyle, and their capacity to bear the psychological and practical costs associated with the intervention. As many of our patients already use commercially available DBCIs "in the wild", outside their structure care regimen, the next steps in the optimization of DBCIs require research conceived and conducted in collaboration with these patients, to better understand the impact of each DBCI component on their lives, and identify ways to reduce it.

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Annexes

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Annex 1: Supplementary article files for Oikonomidi et al, Mayo Clinic Proceedings, 2021

Supplemental Text 1: Survey example (English version)

Please read the description of these three digital tools that can help you monitor your diabetes:

1. A flash continuous glucose monitoring sensor.

The sensor measures your glucose levels continuously. You can use a smartphone application (app) to "scan" the sensor and see: 1) your current glucose levels, and 2) a graph of your glucose levels over the past 8 hours. An arrow shows whether your glucose is increasing, decreasing, or stable.

This sensor consists of a sticky patch and a very small needle that goes under the skin. You can apply it painlessly to your arm and you must change it every 14 days.

2. A smartphone app that monitors your physical activity.

This app measures automatically and continuously: 1) the number of steps you walked and the minutes you exercised daily, and 2) the number of calories you burnt.

To use this app you have to keep your smartphone in your pocket or handbag. If you exercise without your smartphone, you can log the exercise type and duration manually later.

3. A smartphone app that monitors your food intake.

This smartphone app estimates your food intake (calories, nutrients) by automatically analysing photos of your food.

To use it, you have to take a photo of your plate before each meal. You can also manually register your meals later.

What is your age? * _____ years old

You are* ☐ A woman ☐ A man ☐ Prefer to self-describe: _____

Which country do you live in? * _____

At what age did you complete your education? *___ years old

Which type of diabetes do you have? * ☐ Type 1 ☐ Type 2 ☐ Other (please describe) _____

Do you use insulin to manage your diabetes? * ☐ Yes, I use insulin shots ☐ Yes, I use an insulin pump ☐ No

Do you feel your diabetes is well controlled? * ☐ Yes ☐ No

Think of all the things you currently do to monitor your diabetes. This may include finger prick tests, frequent doctor appointments, keeping food and exercise diaries, etc.

1. How intrusive is your current monitoring to your daily life? *

☐	☐	☐	☐	☐
Not at all	A little	Moderately	Very	Extremely

2. How reassured does your current monitoring make you feel? *

☐	☐	☐	☐	☐
Not at all	A little	Moderately	Very	Extremely

Imagine that your doctor prescribes that you use the diabetes monitoring below, at no additional financial cost to you.

Scenario 1/3:

Digital tools:

- A glucose sensor and an app to monitor your physical activity.
- An app to monitor your food intake. You will have to take pictures of only the meals, snacks or drinks that are unusual to what you ordinarily consume.

Monitoring duration:

- This will be your regular monitoring from now on.

Adapting your treatment:

- If an anomaly is detected in the data, your doctor will receive a notification in real time. He/she will then contact you to adapt your treatment if necessary.
- No regular visits will be required to follow-up on your diabetes, but you will be able to make an appointment with your doctor if you wish to.

Data handling:

- Your data will be handled by a private organization (an insurance, a pharmaceutical or an informatics company).

1. How intrusive would this diabetes monitoring be to your daily life? *

☐	☐	☐	☐	☐
Not at all	A little	Moderately	Very	Extremely

2. How reassured would this monitoring make you feel? *

☐	☐	☐	☐	☐
Not at all	A little	Moderately	Very	Extremely

3. How effective would this monitoring have to be at reducing the frequency of hypoglycaemic episodes (low glucose levels), for you to choose it over your current way of monitoring? *

☐	☐	☐	☐	☐
It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective

4. How effective would this monitoring have to be at preventing eye complications in the future, for you to choose it over your current way of monitoring? *

☐	☐	☐	☐	☐
It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective

Imagine that your doctor prescribes that you use the diabetes monitoring below, at no additional financial cost to you.

Scenario 2/3:

Digital tools:

- A glucose sensor and an app to monitor your physical activity.

Monitoring duration:

- This will be your regular monitoring from now on.

Adapting your treatment:

- If an anomaly is detected in the data, your doctor will receive a notification in real time. He/she will then contact you to adapt your treatment if necessary.
- No regular visits will be required to follow-up on your diabetes, but you will be able to make an appointment with your doctor if you wish to.

Data handling:

- Your data will be handled by a private organization (an insurance, a pharmaceutical or an informatics company).

1. How intrusive would this diabetes monitoring be to your daily life? *

☐	☐	☐	☐	☐
Not at all	A little	Moderately	Very	Extremely

2. How reassured would this monitoring make you feel? *

☐	☐	☐	☐	☐
Not at all	A little	Moderately	Very	Extremely

3. How effective would this monitoring have to be at reducing the frequency of hypoglycaemic episodes (low glucose levels), for you to choose it over your current way of monitoring? *

☐	☐	☐	☐	☐
It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective

4. How effective would this monitoring have to be at preventing eye complications in the future, for you to choose it over your current way of monitoring? *

☐	☐	☐	☐	☐
It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective

Imagine that your doctor prescribes that you use the diabetes monitoring below, at no additional financial cost to you.

Scenario 3/3:

Digital tools:

- A glucose sensor and an app to monitor your physical activity.
- An app to monitor your food intake. You will have to take pictures of only the meals, snacks or drinks that are unusual to what you ordinarily consume.

Monitoring duration:

- This will be your regular monitoring from now on.

Adapting your treatment:

- Your data will be used to automatically adapt your treatment. This information will appear on your smartphone in real time.
- No regular visits will be required to follow-up on your diabetes, but you will be able to make an appointment with your doctor if you wish to.
- Your doctor will not receive any real-time notifications.

Data handling:

- Your data will be handled by a private organization (an insurance, a pharmaceutical or an informatics company).

1. How intrusive would this diabetes monitoring be to your daily life? *

☐	☐	☐	☐	☐
Not at all	A little	Moderately	Very	Extremely

2. How reassured would this monitoring make you feel? *

☐	☐	☐	☐	☐
Not at all	A little	Moderately	Very	Extremely

3. How effective would this monitoring have to be at reducing the frequency of hypoglycaemic episodes (low glucose levels), for you to choose it over your current way of monitoring? *

☐	☐	☐	☐	☐
It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective

4. How effective would this monitoring have to be at preventing eye complications in the future, for you to choose it over your current way of monitoring? *

☐	☐	☐	☐	☐

It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective

Finally, please answer the following questions:

Which aspect of the diabetes monitoring scenarios you read did you find most intrusive and why? _____

How would digital diabetes monitoring affect your family, social and professional life? _____

Are you already using a sensor or app for your health or wellbeing (e.g., flash glucose sensor, physical activity wearable, nutrition app)? * ☐ Yes ☐ No

If no: Do you intend to use one in the next 6 months? * ☐ Yes ☐ No

If yes: Do you use it regularly (on several days and every week)? * ☐ Yes ☐ No

If yes, for how many months have you been using it regularly? * ____

How many hypoglycaemic episodes have you had in the last 30 days? * ____

Were any of these episodes so severe that they required assistance from others? * ☐ Yes ☐ No

Have you had any of the following health complications due to your diabetes:

☐ Neuropathic pain ☐ Renal complications ☐ Blindness ☐ Amputation ☐ Stroke ☐ Heart attack ☐ Other: _____ ☐ None

Which of the following diabetes issues are currently a problem for you?

1. Feelings of guilt or anxiety when you get off track with your diabetes management? *

☐	☐	☐	☐	☐
Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem

2. Feeling “burned out” by the constant effort needed to manage diabetes? *

☐	☐	☐	☐	☐
Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem

3. Worrying about the future and the possibility of serious complications? *

☐	☐	☐	☐	☐
Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem

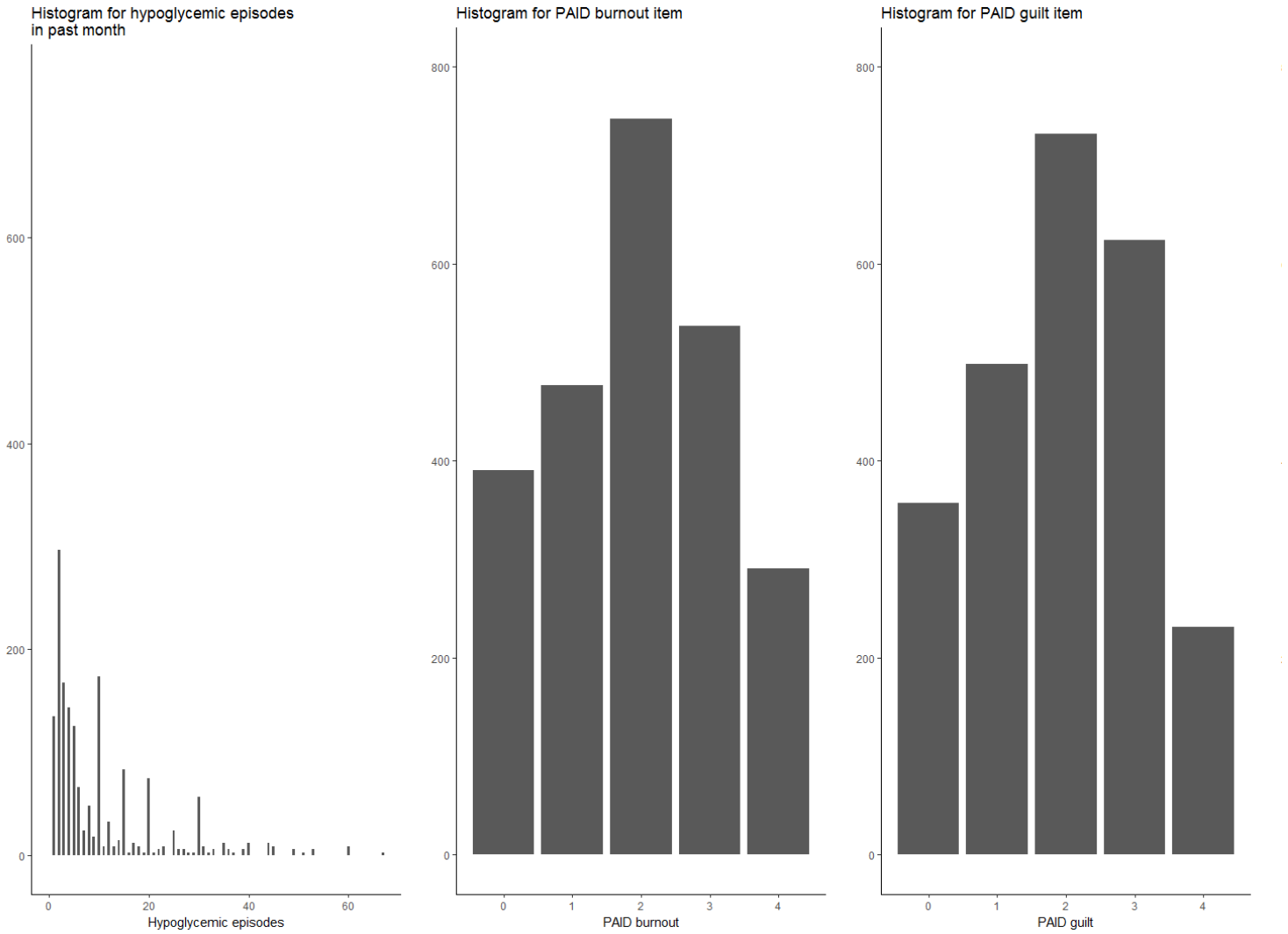
* Required responses

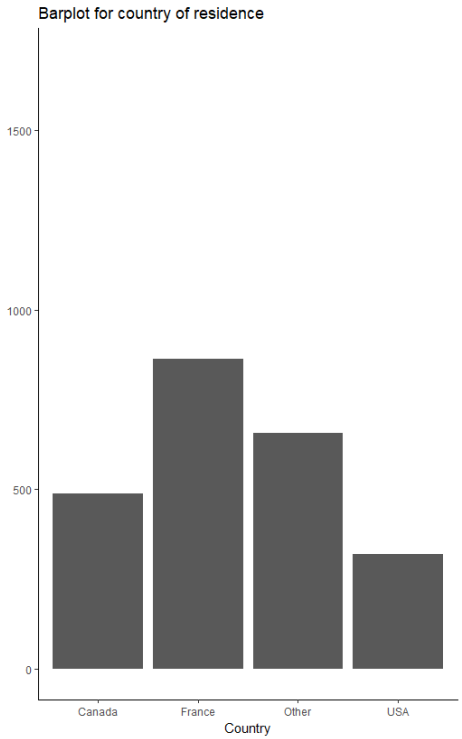
Supplemental Text 2: Model description

Variables entered in the model

All independent variables were selected on the basis of previous publications and clinical experience by a psychologist (TO), 2 diabetologists (VM, EC) and 2 epidemiologists (VTT, PR) to reflect diabetes control and psychosocial aspects of self-management.[56,87] The following independent variables were entered in the theory-driven model: vignette factor 1 (monitoring tools, categorical variable with 3 categories), vignette factor 2 (duration/feedback loop, categorical with 6 categories), vignette factor 3 (data handling, binary), participant age (continuous), insulin use (categorical with 3 categories: no insulin, shots, pump), country (categorical with 4 categories: France, United States, Canada, other), number of hypoglycemic episodes in the last 30 days (continuous), self-reported diabetes control (binary), Problem Areas In Diabetes (PAID) scale item on guilt (continuous), PAID item on burnout (continuous), and current use of digital monitoring (categorical with 3 categories: participants who neither use nor intend to use monitoring tools in the future, participants who intend to use them or use them irregularly, and participants who use them regularly).

I. Distribution of the candidate predictors and outcomes in the complete–case dataset (n=2442)




Barplot for country of residence
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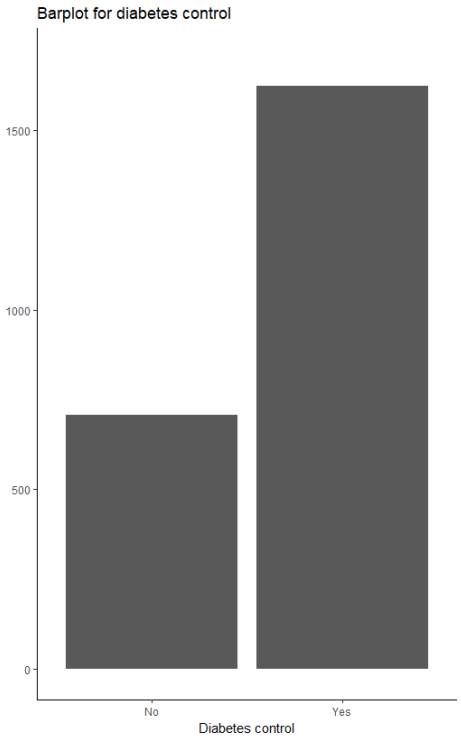
1000
500
0
Canada
France
Other
USA
Country


Barplot for diabetes control
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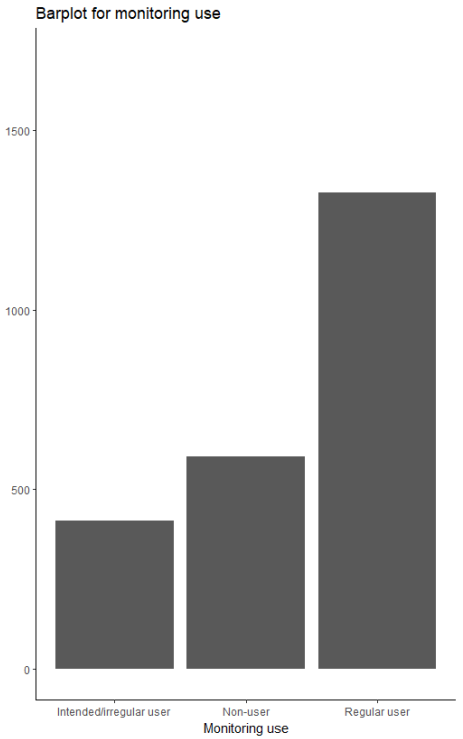
1000
500
0
No
Yes
Diabetes control


Barplot for monitoring use
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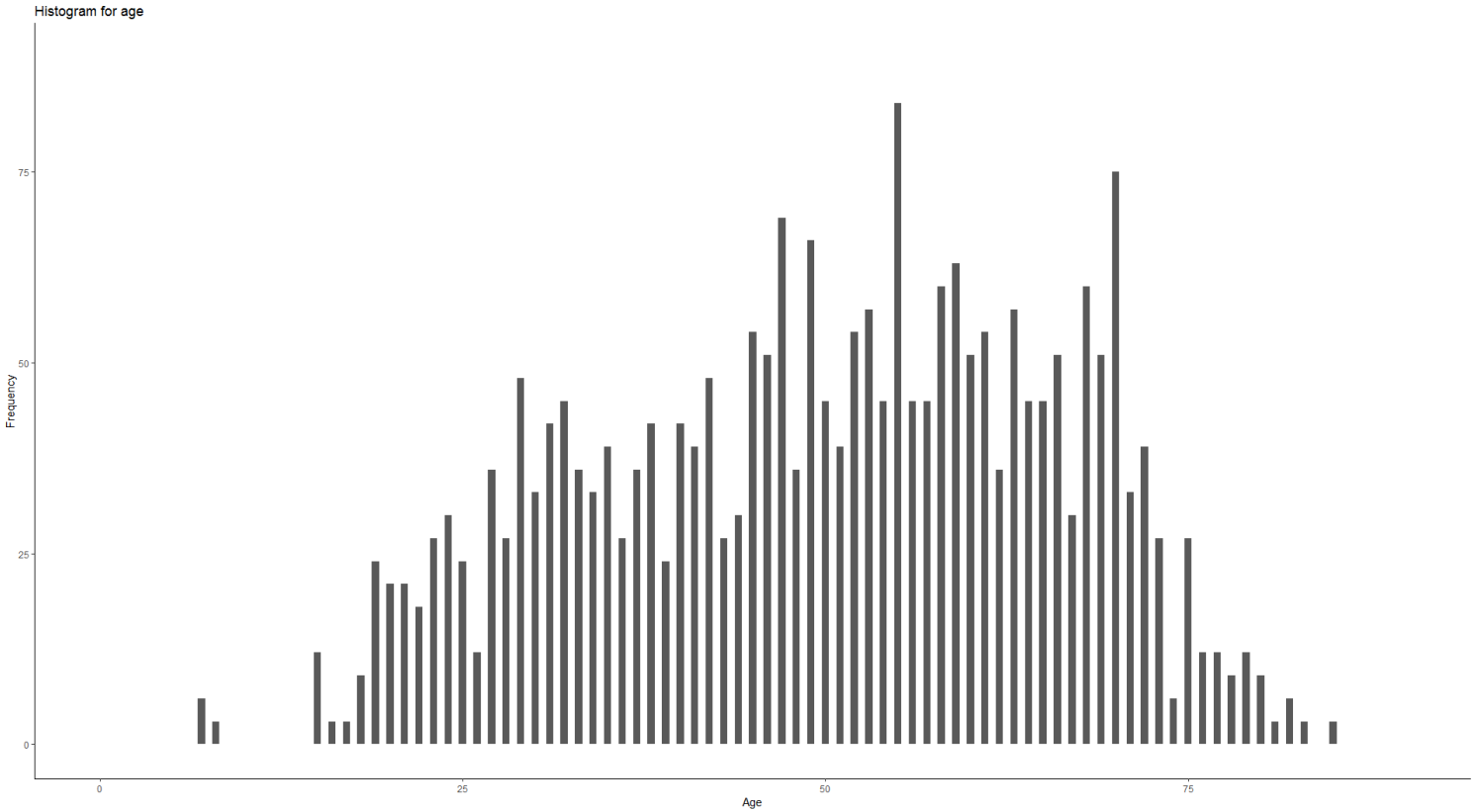
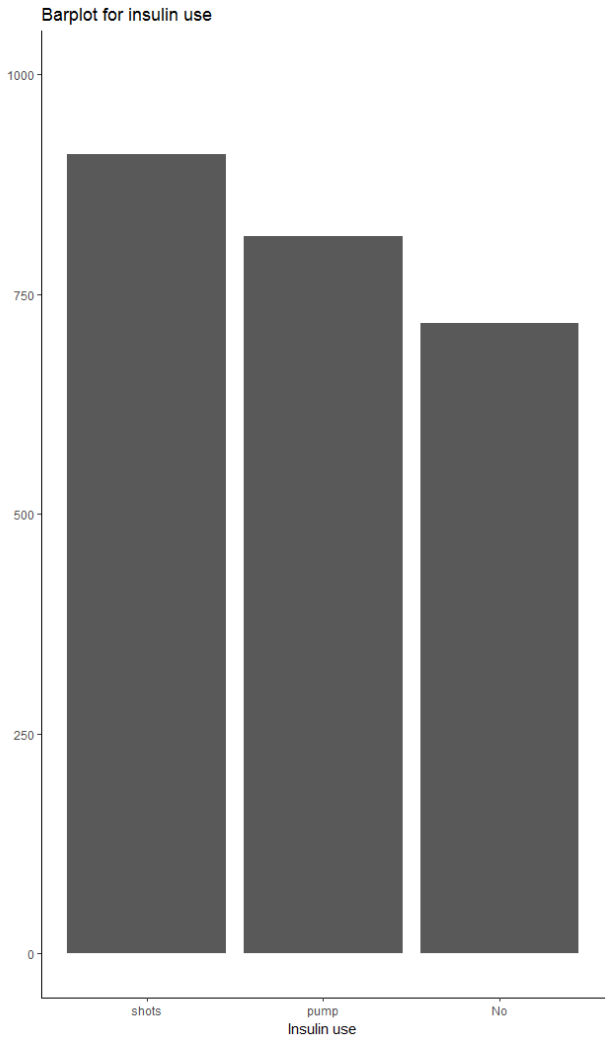
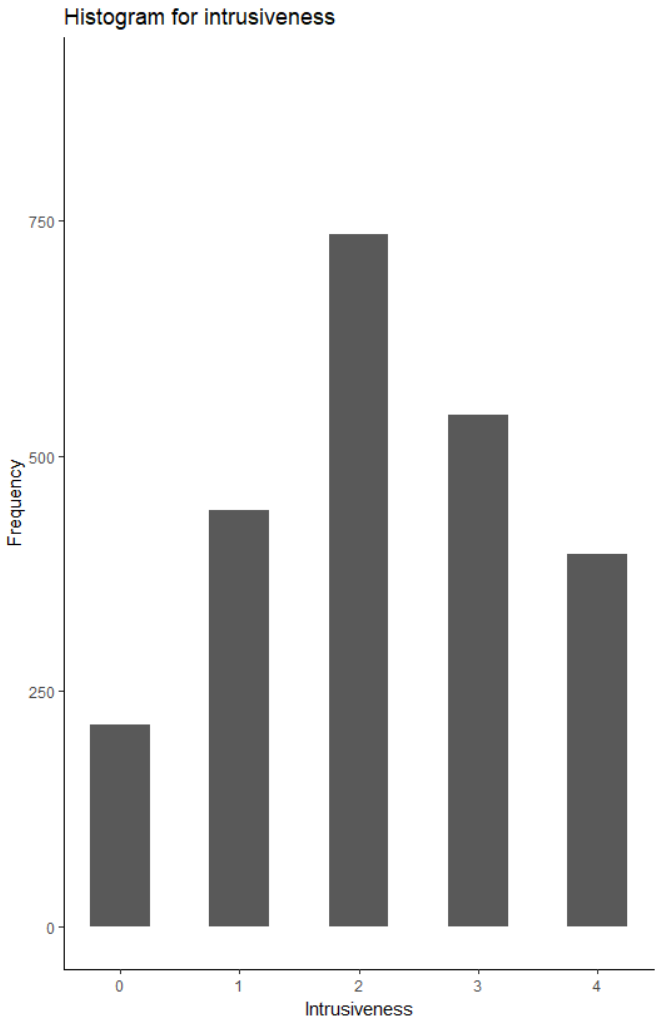
1000
500
0
Intended/irregular user
Non-user
Regular user
Monitoring use


Histogram for age
Frequency
75
50
25
0
0
25
50
75
Age


Barplot for insulin use
1000
750
500
250
0
shots
pump
No
Insulin use


Histogram for intrusiveness
750
500
250
0
Frequency
0
1
2
3
4
Intrusiveness

II. Model fit and selection of predictors

The model was fit in the complete-case dataset (n=2442, representing 85% of the full dataset). Correlations among independent variables were assessed for multi-collinearity. The assumption of normal distribution for the outcome variable was visually assessed in plots.

Starting from the theory-driven model specified above, we removed the weakest predictor based on its coefficient and refit the model. If this step provided improved fit (based on the Akaike information criteria [AIC], smaller values implying a better model fit), the next weakest predictor was removed, until no further improvement in AIC was achieved.

The following predictors were removed to arrive to the final intrusiveness model: age, number of hypoglycemic episodes, 2 levels of the second vignette factor (permanently, with real-time, AI-generated treatment and lifestyle feedback, monitoring for a week before all consultations with feedback in consultation), insulin use (pump and shots) and residence in the United States. Their removal improved model fit (theory-driven model AIC = 6987, final model AIC = 6974).

Supplemental Table 1: Distribution of intrusiveness ratings per vignette

Vignette	n	Intrusiveness rating (%)				
		Not at all	A little	Moderately	Very	Extremely
Glucose and physical activity (PA) monitoring, for a week before a specific consultation with feedback in consultation and public-sector data handling [a]	80	9 (11)	21 (26)	25 (31)	18 (22)	7 (9)
Glucose and PA monitoring, for a week before a specific consultation with feedback in consultation and private sector data handling	78	7 (9)	23 (29)	27 (35)	13 (17)	8 (10)
Glucose and PA monitoring, for a week before all consultations with feedback in consultation and public-sector data handling	76	9 (12)	17 (22)	33 (43)	11 (14)	6 (8)
Glucose and PA monitoring, for a week before all consultations with feedback in consultation and private-sector data handling	86	10 (12)	15 (17)	24 (28)	24 (28)	13 (15)
Glucose and PA monitoring, permanently with real-time feedback by the patient's regular physician and public-sector data handling	79	5 (6)	20 (25)	25 (32)	18 (23)	11 (14)
Glucose and PA monitoring, permanently with real-time feedback by the patient's regular physician and private-sector data handling	79	7 (9)	20 (25)	26 (33)	15 (19)	11 (14)
Glucose and PA monitoring, permanently with real-time feedback by another care professional and public-sector data handling	78	5 (6)	23 (29)	24 (31)	12 (15)	14 (18)

Vignette	n	Intrusiveness rating (%)				
		Not at all	A little	Moderately	Very	Extremely
Glucose and PA monitoring, permanently with real-time feedback by another care professional and private-sector data handling	78	13 (17)	6 (8)	30 (38)	17 (22)	12 (15)
Glucose and PA monitoring, permanently with real-time, artificial intelligence (AI)-generated treatment feedback and public-sector data handling [a]	78	9 (12)	22 (28)	35 (45)	7 (9)	5 (6)
Glucose and PA monitoring, permanently with real-time, AI-generated treatment feedback and private-sector data handling	108	10 (9)	24 (22)	33 (31)	25 (23)	16 (15)
Glucose and PA monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback and public-sector data handling	80	8 (10)	19 (24)	26 (32)	17 (21)	10 (12)
Glucose and PA monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback and private-sector data handling	90	11 (12)	22 (24)	30 (33)	15 (17)	12 (13)
Glucose, PA and regular food monitoring, for a week before a specific consultation with feedback in consultation and public-sector data handling	78	11 (14)	16 (21)	23 (29)	20 (26)	8 (10)
Glucose, PA and regular food monitoring, for a week before a specific consultation with feedback in consultation and private-sector data handling	77	3 (4)	9 (12)	27 (35)	22 (29)	16 (21)

Vignette	n	Intrusiveness rating (%)				
		Not at all	A little	Moderately	Very	Extremely
Glucose, PA and regular food monitoring, for a week before all consultations with feedback in consultation and public-sector data handling	78	9 (12)	16 (21)	20 (26)	18 (23)	15 (19)
Glucose, PA and regular food monitoring, for a week before all consultations with feedback in consultation and private-sector data handling	76	8 (11)	12 (16)	21 (28)	20 (26)	15 (20)
Glucose, PA and regular food monitoring, permanently with real-time feedback by the patient's regular physician and public-sector data handling	79	3 (4)	12 (15)	22 (28)	23 (29)	19 (24)
Glucose, PA and regular food monitoring, permanently with real-time feedback by the patient's regular physician and private-sector data handling	77	5 (6)	11 (14)	20 (26)	29 (38)	12 (16)
Glucose, PA and regular food monitoring, permanently with real-time feedback by another care professional and public-sector data handling	77	9 (12)	13 (17)	14 (18)	24 (31)	17 (22)
Glucose, PA and regular food monitoring, permanently with real-time feedback by another care professional and private-sector data handling	77	8 (10)	11 (14)	20 (26)	21 (27)	17 (22)
Glucose, PA and regular food monitoring, permanently with real-time, AI-generated treatment feedback and public-sector data handling	78	8 (10)	11 (14)	21 (27)	17 (22)	21 (27)

Vignette	n	Intrusiveness rating (%)				
		Not at all	A little	Moderately	Very	Extremely
Glucose, PA and regular food monitoring, permanently with real-time, AI-generated treatment feedback and private-sector data handling	79	8 (10)	11 (14)	25 (32)	20 (25)	15 (19)
Glucose, PA and regular food monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback and public-sector data handling	78	5 (6)	18 (23)	23 (29)	20 (26)	12 (15)
Glucose, PA and regular food monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback and private-sector data handling	79	3 (4)	9 (11)	28 (35)	22 (28)	17 (22)
Glucose, PA and occasional food monitoring, for a week before a specific consultation with feedback in consultation and public-sector data handling	80	13 (16)	21 (26)	22 (28)	19 (24)	5 (6)
Glucose, PA and occasional food monitoring, for a week before a specific consultation with feedback in consultation and private-sector data handling	78	7 (9)	22 (28)	20 (26)	19 (24)	10 (13)
Glucose, PA and occasional food monitoring, for a week before all consultations with feedback in consultation and public-sector data handling	77	5 (6)	8 (10)	27 (35)	18 (23)	19 (25)
Glucose, PA and occasional food monitoring, for a week before all consultations with feedback in consultation and private-sector data handling	77	9 (12)	14 (18)	25 (32)	16 (21)	13 (17)

Vignette	n	Intrusiveness rating (%)				
		Not at all	A little	Moderately	Very	Extremely
Glucose, PA and occasional food monitoring, permanently with real-time feedback by the patient's regular physician and public-sector data handling	79	3 (4)	13 (16)	26 (33)	26 (33)	11 (14)
Glucose, PA and occasional food monitoring, permanently with real-time feedback by the patient's regular physician and private-sector data handling	79	6 (8)	15 (19)	21 (27)	19 (24)	18 (23)
Glucose, PA and occasional food monitoring, permanently with real-time feedback by another care professional and public-sector data handling	77	6 (8)	13 (17)	24 (31)	19 (25)	15 (19)
Glucose, PA and occasional food monitoring, permanently with real-time feedback by another care professional and private-sector data handling	77	5 (6)	15 (19)	19 (25)	19 (25)	19 (25)
Glucose, PA and occasional food monitoring, permanently with real-time, AI-generated treatment feedback and public-sector data handling	78	8 (10)	22 (28)	25 (32)	15 (19)	8 (10)
Glucose, PA and occasional food monitoring, permanently with real-time, AI-generated treatment feedback and private-sector data handling	79	8 (10)	12 (15)	26 (33)	20 (25)	13 (16)
Glucose, PA and occasional food monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback and public-sector data handling	79	15 (19)	15 (19)	23 (29)	14 (18)	12 (15)

Vignette	n	Intrusiveness rating (%)				
		Not at all	A little	Moderately	Very	Extremely
Glucose, PA and occasional food monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback and private-sector data handling	77	5 (6)	18 (23)	23 (30)	19 (25)	12 (16)

[a] PA, physical activity; AI, artificial intelligence

Supplemental Table 2: Characteristics of participants with complete and incomplete data

Characteristics	Complete data (n=814)	Incomplete data (n=196)
Age, median (IQR)	51 [37, 63]	52 [37, 64]
Gender, No. (%)		
Man	311 (38)	83 (42)
Woman	471 (58)	101 (52)
Prefers to self-describe	32 (4)	12 (6)
Country of residence, No. (%)		
France	301 (37)	61 (32)
Canada	171 (21)	40 (21)
United States	110 (14)	28 (15)
United Kingdom	86 (11)	22 (11)
Ireland	60 (7)	22 (11)
Other	84 (10)	20 (10)
Received post-secondary education	584 (71)	143 (73)
Diabetes type, No. (%)		
Type 1	423 (52)	101 (52)
Type 2	340 (42)	71 (36)
Other	51 (6)	24 (12)
Considers diabetes well-controlled	559 (69)	128 (65)
Uses insulin, No. (%) [b]		
Yes, shots	303 (37)	86 (45)
Yes, pump	272 (33)	59 (31)
No	239 (29)	47 (24)

[a] missing in n=4 of participants with incomplete data

Characteristics of participants with complete and incomplete data

Characteristics	Complete data (n=814)	Incomplete data (n=196)
Age, median (IQR)	51 [37, 63]	52 [37, 64]

Gender, No. (%)		
Man	311 (38)	83 (42)
Woman	471 (58)	101 (52)
Prefers to self-describe	32 (4)	12 (6)
Country of residence, No. (%) [a]		
France	301 (37)	61 (32)
Canada	171 (21)	40 (21)
United States	110 (14)	28 (15)
United Kingdom	86 (11)	22 (11)
Ireland	60 (7)	22 (11)
Other	84 (10)	20 (10)
Received post-secondary education	584 (71)	143 (73)
Diabetes type, No. (%)		
Type 1	423 (52)	101 (52)
Type 2	340 (42)	71 (36)
Other	51 (6)	24 (12)
Considers diabetes well-controlled	559 (69)	128 (65)
Uses insulin, No. (%) [b]		
Yes, shots	303 (37)	86 (45)
Yes, pump	272 (33)	59 (31)
No	239 (29)	47 (24)

[a] missing in n=3 of participants with incomplete data

[b] missing in n=4 of participants with incomplete data

Supplemental Table 3: Semi-partial R^2 for the linear mixed models (estimated with the r2glmm R package by using the standardized generalized variance approach)

	Complete case (n=2442)		Multiple imputation (n=2860)	
Effect	**R^2**	**95% CI**	**R^2**	**95% CI**
Model	0.11	0.10 – 0.14	0.09	0.08 – 0.12
Vignette-level predictors				
Monitoring tools (reference category: glucose and PA)				
Glucose, PA and regular food monitoring	0.02	0.01 – 0.03	0.02	0.01 – 0.03
Glucose, PA and occasional food monitoring	0.01	0.006 – 0.03	0.009	0.004 – 0.02
Duration/feedback loop (ref. cat.: for a week before a specific consultation, with feedback in consultation)				
Permanently, with real-time feedback by the patient's regular physician	0.01	0.002 – 0.01	0.007	0.002 – 0.01
Permanently, with real-time feedback by another care professional	0.004	0.001 – 0.01	0.004	0.001 – 0.009
Permanently, with real-time, artificial intelligence-generated treatment feedback	0.001	0.0 – 0.005	0.001	0.00 – 0.004
Data handling (ref. cat.: private-sector data handling)				
Public-sector data handling	0.01	0.001 – 0.01	0.005	0.001 – 0.01
Participant-level predictors				
Feeling "burned out" by the constant effort needed to manage diabetes (PAID questionnaire item)[c]	0.01	0.005 – 0.02	0.01	0.005 – 0.02
Feelings of guilt or anxiety when you get off track with your diabetes management (PAID questionnaire item)	0.01	0.004 – 0.02	0.008	0.003 – 0.02
Current use of digital monitoring tools for health or wellbeing purposes (ref. cat.: does not use them and does not intend to)				
Intends to use them or uses them irregularly	0.03	0.02 – 0.05	0.02	0.009 – 0.03
Uses them regularly	0.01	0.005 – 0.02	0.006	0.001 – 0.01
Well-controlled diabetes (self-reported)	0.004	0.001 – 0.01	0.002	0.00 – 0.007
Gender (ref cat: woman)				
Man	0.01	0.001 – 0.01	0.005	0.001 – 0.01
Prefers to self-describe	0.001	0.00 – 0.005	0.000	0.000 – 0.002
Country of residence (ref. cat.: France)				
Countries other than France, United States and Canada	0.02	0.01 – 0.04	0.02	0.01 – 0.04
Canada	0.003	0.00 – 0.008	0.004	0.001 – 0.01

Supplemental Table 4. Linear mixed model of intrusiveness fit in the complete-case subset (n=2442).[a,b]

Predictors	Estimates	95% CI	p
(Intercept)	2.30	2.04 – 2.57	<.001
Vignette-level predictors			
Monitoring tools (reference category: glucose and PA)			
Glucose, PA and regular food monitoring	0.36	0.27 – 0.44	<.001
Glucose, PA and occasional food monitoring	0.29	0.20 – 0.38	<.001
Duration/feedback loop (ref. cat.: For a week before a specific consultation, with feedback in consultation)			
Permanently, with real-time feedback by the patient's regular physician	0.23	0.13 – 0.33	<.001
Permanently, with real-time feedback by another care professional	0.19	0.09 – 0.29	<.001
Permanently, with real-time, artificial intelligence-generated treatment feedback	0.09	-0.01 – 0.19	.070
Data handling (ref. cat.: private-sector data handling)			
Public-sector data handling	-0.15	-0.22 – -0.08	<.001
Participant-level predictors			
Feeling "burned out" by the constant effort needed to manage diabetes (PAID questionnaire item)[c]	0.12	0.05 – 0.19	.001
Feelings of guilt or anxiety when you get off track with your diabetes management (PAID questionnaire item)	-0.11	-0.18 – -0.04	.002
Current use of digital monitoring tools for health or wellbeing purposes (ref. cat.: does not use them and does not intend to)			
Intends to use them or uses them irregularly	-0.57	-0.78 – -0.36	<.001
Uses them regularly	-0.27	-0.44 – -0.11	.001
Well-controlled diabetes (self-reported)	0.15	-0.01 – 0.31	.06
Gender (ref. cat.: woman)			
Man	-0.16	-0.30 – -0.02	.02
Prefers to self-describe	0.14	-0.20 – 0.49	.42
Country of residence (ref. cat.: France)			
Canada	-0.14	-0.31 – 0.04	.13
Countries other than France, United States and Canada	-0.37	-0.53 – -0.21	<.001

[a] Representing 85% of the full dataset, vignette-assessments provided by 814 participants.
[b] P-values estimated by Satterthwaite's two-sample t-test for degrees of freedom
[c] PAID, Problem Areas In Diabetes; CI, confidence interval

Supplemental Table 5. Cumulative link mixed model of intrusiveness fit in the complete-case subset (n=2442) and in the imputed dataset (n=2860).[a,b]

	Complete case (n=2442)					Multiple imputation (n=2860)				
Predictors	**Estimate**	**SE[c]**	**ORs[c]**	**95% CI**	**p**	**Estimate**	**SE**	**ORs**	**95% CI**	**P**
Intercept: Not at all | A little	-4.42	0.39	0.01	0.01 – 0.03	<.001	-4.35	0.36	0.01	0.01 – 0.03	<.001
Intercept: A little | Moderately	-2.01	0.37	0.13	0.06 – 0.28	<.001	-1.84	0.34	0.16	0.08 – 0.31	<.001
Intercept: Moderately | Very	0.41	0.37	1.51	0.73 – 3.10	.27	0.56	0.34	1.76	0.90 – 3.44	.10
Intercept: Very | Extremely	2.57	0.37	13.06	6.27 – 27.18	<.001	2.79	0.35	16.25	8.20 – 32.20	<.001
Vignette-level predictors										
Monitoring tools (reference category: glucose and PA)										
Glucose, PA and regular food monitoring	0.95	0.12	2.59	2.06 – 3.26	<.001	0.92	0.11	2.50	2.02 – 3.09	<.001
Glucose, PA and occasional food monitoring	0.78	0.12	2.18	1.73 – 2.73	<.001	0.68	0.11	1.98	1.60 – 2.45	<.001
Duration/feedback loop (ref. cat.: For a week before a specific consultation, with feedback in consultation)										
Permanently, with real-time feedback by the patient's regular physician	0.61	0.13	1.84	1.43 – 2.38	<.001	0.67	0.12	1.94	1.53 – 2.47	<.001

Permanently, with real-time feedback by another care professional	0.49	0.13	1.64	1.26 – 2.13	<.001	0.48	0.13	1.61	1.26 – 2.06	<.001
Permanently, with real-time, artificial intelligence-generated treatment feedback	0.20	0.13	1.22	0.95 – 1.56	.13	0.17	0.12	1.19	0.94 – 1.50	.14
Data handling (ref. cat.: private-sector data handling)										
Public-sector data handling	-0.38	0.09	0.68	0.57 – 0.82	<.001	-0.39	0.09	0.68	0.57 – 0.80	<.001
Participant-level predictors										
Feeling "burned out" by the constant effort needed to manage diabetes (PAID questionnaire item)[c]	0.32	0.10	1.38	1.14 – 1.67	.001	0.30	0.08	1.35	1.15 – 1.60	<.001
Feelings of guilt or anxiety when you get off track with your diabetes management (PAID questionnaire item)	-0.33	0.10	0.72	0.59 – 0.88	.001	-0.29	0.09	0.75	0.63 – 0.88	.001
Current use of digital monitoring tools for health or wellbeing purposes (ref. cat.: does not										

use them and does not intend to)										
Intends to use them or uses them irregularly	-1.53	0.30	0.22	0.12 – 0.39	<.001	-1.15	0.23	0.32	0.20 – 0.50	<.001
Uses them regularly	-0.74	0.23	0.48	0.31 – 0.75	.001	-0.49	0.19	0.62	0.43 – 0.89	.009
Well-controlled diabetes (self-reported)	0.40	0.22	1.49	0.97 – 2.28	.07	0.33	0.20	1.39	0.93 – 2.06	.10
Gender (ref. cat.: woman)										
Man	-0.42	0.20	0.66	0.45 – 0.97	.04	-0.42	0.18	0.66	0.46 – 0.95	.02
Prefers to self-describe	0.32	0.49	1.38	0.53 – 3.58	.51	0.07	0.43	1.08	0.46 – 2.51	.86
Country of residence (ref. cat.: France)										
Canada	-0.34	0.24	0.71	0.44 – 1.15	.17	-0.45	0.23	0.64	0.41 – 0.99	.05
Countries other than France, United States and Canada	-1.02	0.22	0.36	0.23 – 0.56	<.001	-1.05	0.21	0.35	0.23 – 0.52	<.001

[a] For the complete-case dataset: AIC = 6630, pseudo-R2 = 0.081 (estimated for the model vs the null using Nagelkerke's method)

[b] For the imputed dataset: AIC = 7729, pseudo-R2 = 0.09, (estimated for the model vs the null using Nagelkerke's method)

[c] SE, standard error; OR, odds ratio

Supplemental Table 6: Qualitative analysis results

Codebook

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
Burden					
	Task-related burden (6)				
		Monitoring burden	Burden linked to practical tasks involved in remote digital monitoring. Includes the act of monitoring glucose levels and device maintenance.	Needing to carry all the stuff and make sure its readily available. Add to that ordering and maintaining supplies and sometimes the logistical details can be overwhelming. (W, age 54, T2) [a] Using technology. Its time-consuming and a faff [waste of time]. (W, 52, T1) [a]	88
		Food monitoring burden	Burden linked specifically to monitoring food intake.	Photographing my food would add another step to the faffing [wasting time with] with glucose monitoring and an injection at every meal. (W, 38, T1) Having to take a picture of your food; having to put your exercise in. (W, 41, T2)	96
		Time burden	Taking the time required to perform monitoring tasks.	All three are intrusive because the monitoring takes time and effort. (M, 69, T2) [a] Logging food, because I did that before for other health problems, and it was difficult and time-consuming. (M, 23, T1)	54
		Cognitive burden	Difficulty in remembering or understanding how to use monitoring correctly.	I also would have a hard time in scenario 3 figuring out what are the foods I don't normally consume, as I eat a varied diet. (W, 41, T2; scenario 3 included monitoring unusual meals) Having to photograph meals presumably including in	19

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
				restaurants. Remembering to do this at the appropriate times might be difficult. (M, 68, T2)	
		Multiple devices	Having to use multiple devices and software instead of a single monitoring device and app.	Although I like the idea of them all, it's the fact that they are 3 different apps, which would be very time-consuming. (W, 54, T2) The apps and sensors are good way forward in managing and monitoring but would be best in one tool. (M, 58, T1)	10
		Having to adapt lifestyle	The participant would have to change the way they live to fit the monitoring in their life (e.g., change their mealtime routine, swap their clothes for long-sleeved ones that hide the wearable).	I rarely carry a purse, so unless I can wear the device(s), this will be a huge change for me. (W, 59, T2) Don't like the glucose monitoring device on the arm, you would feel you have to always cover it up, which is not great for women in the summer. (W, 68, T2)	13
	Disruption (3)				
		Disruptive alerts	Disruption in patients' daily life caused by alerts and notifications. Includes mentions of alert fatigue.	Untimely alarms during meals, meetings, work or family functions. (Other/undisclosed, 37, T2) The results are good, but the constant incessant presence of reminders and alerts is tiring. (W, 51, T1)	9
		Disruptive food monitoring	Disruption caused by monitoring food intake, particularly disruption of the social nature of mealtimes (i.e.,	Photos of food, because it interrupts a ritual. (M, 42, Other diabetes diagnosis) Having to take photos of everything I eat for any amount of	12

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
			as a family ritual or a convivial activity).	time would be very intrusive. When my meal is ready I want to eat it, not take photos of it. (W, 67, T1)	
		Interrupted access to the monitoring device	The monitoring device is inaccessible in some settings (e.g., restaurants that do not allow food photography). Having to use this device disrupts regular monitoring and discourages the participant from relying on it.	I am not allowed to take personal calls while in work this scenario would actually cost me my income if I tried to implement it. (W, 24, T1) (the scenario described real-time notifications sent to one's doctor if an anomaly was detected in the data, who would then decide to contact the participant as needed) I also work and travel in places where communication (and electricity) is limited and therefore cannot depend on anyone or anything else for my well-being. (W, 46, T1)	8
	Physical intrusion (4)				
		Constant device wear	Having to continuously wear or carry the monitoring device on one's person.	The smartphone app that tracks physical activity. I would find having to permanently carry my smartphone on me to be too much of a constraint. (W, 61, 2) Exercise app and CGM. I find wearables very intrusive (W, 53, T2)	41
		Limits physical activity	Concerns about limitations in physical activity, including sports and sex, imposed by the wearable device.	Definitely the disc with the needle would appear to be intrusive as I swim a lot while on vacation and at home, year round, and if that is a factor that would limit its effectiveness. (M, 74, Other diabetes diagnosis) I work out a lot, and I feel like the sensor would limit my ability to move freely. (M, 69, T2)	11

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
		Constant microneedle wear	Dislike having a microneedle permanently inserted in one's body (part of the wearable glucose sensor).	The continuous monitor patch with the needle always being under the skin, that sounds very painful, like having an IV for the rest of your life. (M, 29, T1) I find it intrusive when having to put a patch on your arm using a needle to monitor blood sugars daily. I would rather use finger picking. (W, 62, T2)	9
		Adverse events	Concerns about potential physical adverse events from the wearable glucose sensor.	The glucose monitor needle under the skin - may be uncomfortable or prone to infection. (W, 52, T2) The sensor. I have already had sensors implanted, it's horrible. Pain, swelling, my body rejects it completely. I can tolerate it for a couple days, but no more. (W, 61, T2)	9
	Emotional burden (3)				
		Stress and mental load	Concern about the stress or the mental load that would result from the proposed monitoring.	I'd have to integrate it in my self-management routine, but I've the impression that it would be an additional challenge, an additional mental load. (W, 53, T1) The stress of using any of the described scenarios is unneeded. (M, 83, T2)	23
		Impression of failure	Concern that the monitoring data would make the participant feel as if they are failing to manage their diabetes.	Oftentimes the constant monitoring can just be a reminder of your failure in many ways. I have depression and anxiety and digital monitoring can add a lot of extra mental pressure which compounds these issues. (W, 26, T1) [I would experience] the feeling of failing in my treatment and self-management. (W, 53, T2)	2

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
		Reminder of diabetes	The monitoring would become a reminder of having diabetes, making the participant think of diabetes more, or otherwise increase the presence of diabetes in the participant's life.	I think this constantly present medical follow-up would not let us forget the illness any more... And sometimes we need to not think of it. (W, 42, T1) Further monitoring would involve further alienation from my "normal" relationships. It is a form of more intense treatment, with the benefit of better health outcomes. The current digital diabetes tools that I use have increased the presence of my disease in my life, not decreased it through technological ease. (M, 23, T1)	24
	Social burden (5)				
		Visibility	The sensor or the act of monitoring using the smartphone app is easily visible to others in public spaces.	Keeping a record and pictures of the food intake every 3 days. People will see you take pictures of your food. (W, 32, T1) The sensor is really visible. (W, 32, T1)	34
		Indescretion/awkwardness	The monitoring device, or the act of monitoring (e.g., taking photos) is too awkward or indiscrete for use in social settings, including the workplace and restaurants.	While convenient, taking photos of food that I eat would be awkward in social situations, more so than my current carb counting methods. (W, 60, T1) All 3 are intrusive because the monitoring takes time and effort. It would be silly taking pictures of food servings at restaurants. (M, 61, T2)	30
		Attracting attention in public	The monitoring device, or the act of monitoring would “invite” staring, personal questions, or indiscrete comments from others.	The fact that people would stare at my devices and ask questions [is intrusive]. (W, 28, T1) [The] sensor on arm at all times. [I] would get lots of questions when people see it for first time. (M, 63, T2)	40

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
		Being 'exposed'	The monitoring device, or the act of monitoring would "expose" the participant as diabetic, forcing them to "come out" to others who were previously unaware of the diagnosis.	This would only affect my professional life, because in certain situations I prefer to not say that I have type 2 diabetes. (58) It is uncomfortable that everyone will know that I have diabetes. (W, 68, T1)	11
		Burden to informal caregivers	Monitoring would impose burdens (similar to the ones mentioned above, e.g., disruption, stress) on family and friends.	My husband would worry about me in situations where I am not worried because he isn't in my body, feeling what I am feeling, and it would be unnecessary stress for us both. (W, 26, T1) Notifications during the night wake my husband. (W, 40, T1)	5
Control					
	Need to control monitoring (3)				
		Control over data sharing	Concerns about sharing the monitoring data, either with specific stakeholders (e.g., employer, doctor), or transmitting data outside the participant's own devices in general. Includes comments on wanting control over data sharing (e.g., control who can	I would not want my family checking up on it though. I certainly would not want my boss checking up on it. (W, 55, T1) Knowing that a private-company is managing my data bothers me, unless I have direct control over the captured data. (M, 66, T2)	164

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
			access their data by individually approving each access request), and blocking real-time alerts to physicians.		
		Control over monitoring use	Wanting to control the way in which the monitoring would be applied, for example, to monitor only some of the variables included in the vignette, or only during certain periods (e.g., initial patient education).	Maybe you should think of an "à la carte" system, for those who, for example, do not have glycemic control as the main objective. (Other/undisclosed, 63, T1) The app that tracks your exercise seems great, I don't have one right now, I've my personal system of keeping track but this would be more accurate. As long as I can choose to use it or not, depending on the context, it wouldn't be intrusive; same for the photo app that tracks meals. (W, 38, T1)	4
		Control over feedback	Concerns about receiving feedback on the monitoring data, mentions of wanting to control or limit being contacted with feedback.	Someone getting my data in real time and contacting me about it [is intrusive], because diabetes educators are judgmental and not helpful. (W, 33, T1) [B]eing contacted when they see something they don't like feels like a horror scenario from a famous book. My endo may look at the information from my glucose sensor when I'm there, not remotely. (Other/undisclosed, 42, T1)	30
	Autonomy and freedom (5)				
		Loss of autonomy	Explicit mentions of monitoring reducing the participant's autonomy and freedom/free will.	While it wouldn't affect my family or social life, it would have an enormous impact of my free will and would dehumanize my relationship with my doctor and with the illness itself. (W, 24, T1) The systematic use and the nutrition monitoring [are intrusive].	20

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
				It does not allow any freedom in how I choose to eat. (M, 56, T2)	
		Living under surveillance	The sensation of being monitored, "watched", of living under continuous, permanent surveillance.	What's intrusive is having people observe your life 24/7... "big brother" is among us. (Other/ undisclosed, 61, T1) I'd feel permanently under surveillance, permanently judged. (W, 64, T2)	64
		Negates patient expertise	The monitoring and feedback bypass the patient, not taking into account the expertise they have accumulated with experience. The patient loses control over the management of their own health.	And then in all these scenarios someone else is to manage my T1 [diabetes]? I have a much better feel and know more than my doctors, so why should control be taken out of my hands. (W, 55, T1) Doctors being notified in real-time [is intrusive]. I am aware of the variables affecting my blood sugar, so if the doctor is informed of anomalies, I'm already aware and making changes. (W, 27, T1)	42
		Judgment and shaming	Concerns around being judged, criticised, or shamed about one's health behaviors or diabetes management outcomes, by the recipient of the monitoring data.	The scenarios in which my food intake was tracked combined with a human response to anomaly. I do not like the idea of being "lectured" so to speak, on decisions I make regarding what I ate and why. (M, 34, T1) I would find it super intrusive to be followed and judged on my food intake and exercises. We have this disease for life. Of course we cannot be 100% of the time on point on food and exercise. We are not machines. (W, 29, T1)	25
		Reveals "suboptimal" behavior	Concerns about behavioral "slip-ups" being revealed in the monitoring data, when they	Wearing a sensor gives me the impression of being constantly under surveillance. Of being unable to make a minor slip-up without it being visible in the daily [glucose] curve, while it	26

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
			would not have been visible in the participant's regular follow-up.	would have gone more or less unnoticed with glycated hemoglobin. (W, 47, T1) Having to systematically reveal what I eat, because sometimes I slip up, but then I make up for it over the next few days by doing an extra workout or by watching what I eat... (M, 59, T2)	
	Hesitation to depend on a device (4)				
		Dependence on a device	Concern about the role the device takes in diabetes management, reducing the active role of the patient, and about having to return to self-management in the case of technical failure.	Coming to rely completely on a machine would be a major inconvenience if it breaks down, unless there is a backup solution offered to patients, parallel to the main device. (W, 47, T1) The intrusive component of the digital world is [that] the machine determines diabetes management and we come to be a slave to it; this can become burn-out in management. What is the backup plan when apps/tools fail? (M, 58, T1)	10
		Doubts the performance of the digital follow-up	Doubts the accuracy, usefulness, relevance or efficacy of the proposed follow-up.	For starters, as a type 1, taking pictures of meals doesn't make sense. Food for me (and probably most T1s) is the easy part of managing our condition. It's all the other variables which cause blood sugar to fluctuate (hormones, stress, device issues, etc.) that are tricky. Also, dealing with a hypo after-the-fact is useless because no 2 days with T1 are the same. What worked one day won't work the next, so retrospectively looking at data is pretty useless most of the time. (W, 48, T1) Food intake monitoring only makes sense leading up to a diagnostic appointment, and only when used with additional lab testing. (W, 38, T1)	27

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
		Doubts the performance of the digital device	Doubts the device accuracy or durability.	[A]lso how do you know if you are getting the right information from the apps....who regulates them. (W, 54, T2) I am uncomfortable with using a cell phone as a medical device receiver for a variety of reasons, including increased application security risks and durability of hardware. (There's no way that I won't drop and break a cell phone with low blood sugar. It is far more complicated to operate in a state of altered consciousness, compared with my current receiver.) (W, 37, T1)	15
		Non-adherence	Participants state they would not adopt digital monitoring or they would not perform certain monitoring tasks in certain contexts (e.g., at work, in public)	I would hate it and not only stop monitoring, but would leave a practice that forced or pressured me to do these things. People need to manage diabetes, but they also need to have a life. (W, 47, T2) If these programs were entirely voluntary, that would be fine but I doubt I'd volunteer. (M, 63, T1)	13
Data safety and misuse					
	General concerns (2)				
		Data safety concerns	Concerns about data leaks due to illegal activity (data piracy, database hacking).	The fact that the data is saved on servers [is intrusive] because they could be used for purposes other than to help me with my treatment (M, 47 years old, Type 1) I trust neither data management companies nor informatics systems; they are still potentially hackable (M, 70, T2)	19

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
		Data misuse concerns	Concerns about the monitoring data being used in ways not explicitly linked to the participant's care, including marketing and selling data to third parties for profit.	Data handling by a private-organization ... Can we be sure that our health data will not be monetized, for example by health insurance companies? (M, 62, T2) Data going to insurance companies. I currently am not covered and would find the release of my medical information objectionable and would be suspicious of becoming a target for marketing (W, 59, T1)	33
	Stakeholder-specific concerns (4)				
		Public-sector involvement	Mistrust or concerns stated specifically in relation to public-sector involvement in monitoring.	I have an issue with my information being sent to a public-facility. (M, 28, T1) I think the public-storage of data is the most intrusive because public-data eventually can be exploited more easily. (M, 57, T1)	8
		Private-sector involvement	Mistrust or concerns stated specifically in relation to private-sector involvement in monitoring.	The fact that pharmaceutical companies could access the data does not inspire confidence. (M, 23, T1) The most intrusive aspect for me is the scenario where the management is done by a private-company, I outright refuse to do that. (W, 32, T1)	119
		Financial consequences	Potential financial consequences of insurance companies accessing the monitoring data.	Insurance companies would 100% screw you over on coverage if they feel you don't need your [prescription] or that you are not doing enough to warrant type 1 diabetes coverage, which would be devastating to a financially struggling type 1 diabetic who already cannot afford her healthcare. (W, 36, T1) That my private-insurance company would have access to my daily blood glucose data and could in theory use it to increase	11

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
				my costs, not cover my devices or deny me coverage. (W, 31, T1)	
		Diverging stakeholder interests	Concern about the different, unaligned interests of the stakeholders involved in monitoring. Includes comments on the legitimacy of private-sector involvement in health care management.	The fact that the data will be transmitted to people I do not know, and especially that they will be accessible to insurance companies or other private-organizations that are not intended to help me in the management of my illness. (W, 49, T1) I don't feel private companies should have access to a patient's health records. We need to maintain a divide between those requiring health care and the companies who may profit from supplying medicines and equipment. (M, 31, T1)	16
Dehumanization of care					
		Reduces the physician's role	Concerns about the minimization of the role of the physician. This reduction is seen as the result of automatizing feedback, the absence of in-person appointments, or the provision of feedback by an organization (e.g., a professional in a telemonitoring center) versus a physician that the patient has	[T]aking photos of meals and having an organization (versus a doctor) analyze and collect the data would create issues, especially in the United States would open doors to more issues and less help. A personal relationship with a doctor would be easier and more helpful, I would think. (M, 38, T1) I think it's necessary for patients to see their diabetologist once per trimester, so the diabetologist can get a “feel” of the patient and their lifestyle and take these into account alongside the lab test results. (M, 54, T2)	21

Themes	Category (n of codes)	Codes	Definition	Examples	Prevalence (n participants)
			formed a personal relationship with.		
		Dehumanises the patient	Concerns that the monitoring reduces a patient to little more than their data, making them another numerical value among millions.	The constant impression of being a lab rat and that my diabetes data are trivialized... To be just one case among millions.... It's missing the human dimension. (W, 46, T1) It's not so much the intrusion that poses a problem; it's rather the feeling of having my follow-up done by a "machine" and being reduced to a bunch of numbers. (W, 53, T2)	13

[a] M, man; W, woman; T1, type 1 diabetes; T2, type 2 diabetes

Additional codes

The codes below were also identified in the thematic analysis, but were not considered to represent aspects of remote digital monitoring intrusiveness. Therefore, we present them separately from the 4 themes that were retained in the thematic analysis.

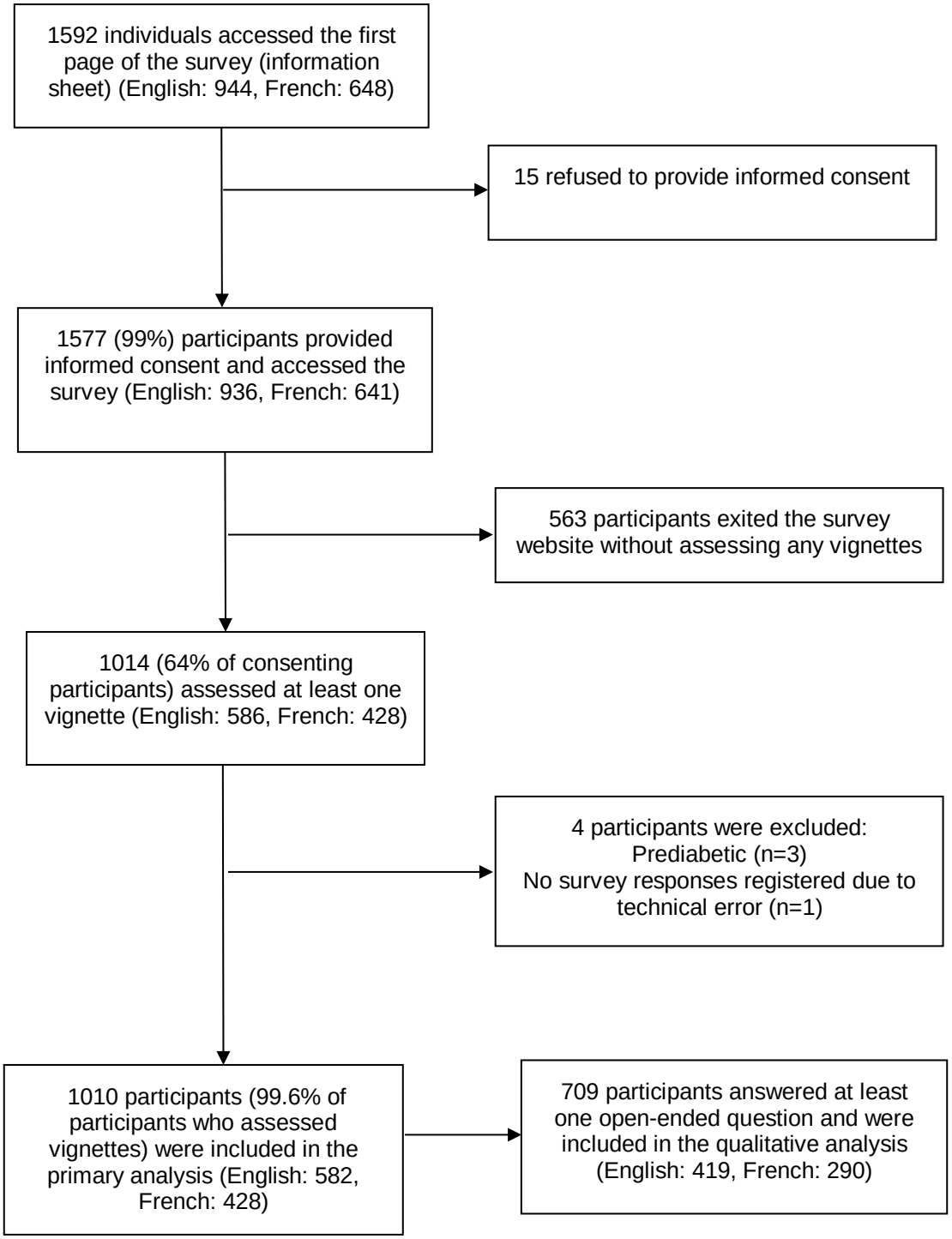
Themes	Codes	Definition	Examples	Prevalence (n of responses)
Benefits				
	Reduces burden	Digital monitoring improves the practical (e.g., number of monitoring tasks) or psychosocial aspects of	It would give me a more frequent reading than 2 times a day, as my day is very busy. This meter seems so simple. (W, 76, T2) Not having to think of medical appointments and try to fit them into	67

Themes	Codes	Definition	Examples	Prevalence (n of responses)
		burden (e.g., makes glucose monitoring more discreet in public-spaces).	my schedule, what with work and the kids, it's a weight off my shoulders. (M, 72, T2)	
	Improves diabetes control	Adopting digital monitoring would lead to better diabetes control (e.g., by enabling behavior change, providing motivation for self-management, or offering a closer follow-up).	I think constant monitor would be quite effective in helping control high sugar. (W, 68, T2) I didn't feel that any aspect presented itself as being intrusive as the monitoring would supply the necessary info to correctly adjust my care. (M, 69, T2)	76
	Improves life	Mentions of a better life quality as an outcome of digital monitoring, without specifying if that results from burden reduction or better diabetes control.	These technology advances are important for diabetic people. They enable us to have a better day-to-day life. (W, 29, T1) It would positively impact my daily lifestyle. (M, 30, T2)	31
	Reassures me	Digital monitoring would be reassuring to the participant	That wouldn't affect me negatively, because I'd feel so much more confident. (W, 52, T1) I wouldn't feel “managed”, but protected. (W, 49, T1)	18
	Reassures others	Digital monitoring by the participant would be reassuring to others, such as family	It would put my family at ease as they know I am using the best tools available. (W, 29, T1) It would probably put my family at ease a bit more and my employer can rest easy knowing that I'm doing my best to control my diabetes. (W, 24, T2)	18
	Increases autonomy	Digital monitoring could increase the participant's autonomy	It would offer me more autonomy, a better life. (W, 42, T1) It would allow me to go out with friends and family more often and that would improve my life. (M, 54, T1)	8

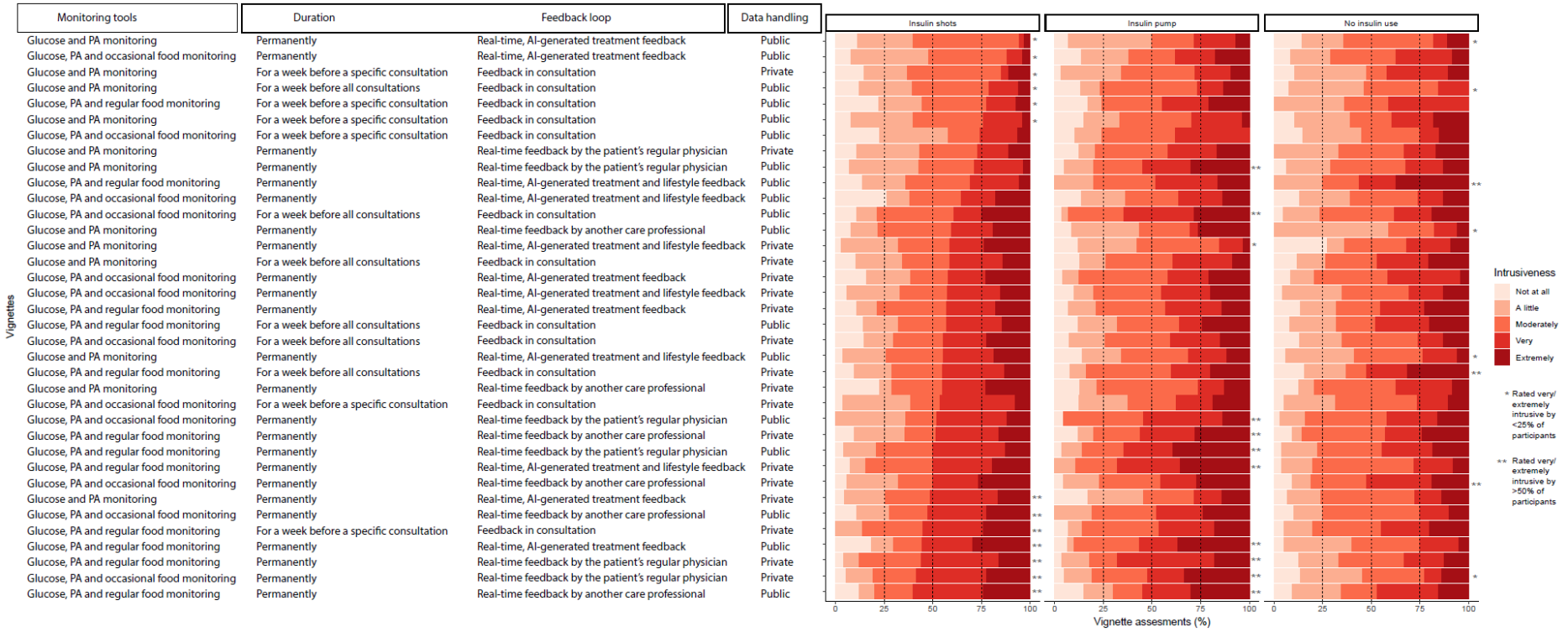
Themes	Codes	Definition	Examples	Prevalence (n of responses)
Uncategorized				
	Not intrusive	The monitoring is not considered intrusive	Would not be intrusive on my life (M, 50, T1)	38
	Negligible impact	The monitoring would impact the participants life very little or not at all.	It has no real impact on my life. (M, 62, T2) I don't really have a social or family life, I go out for a cup of coffee or lunch with my friend sometimes, so logging a photo of my meal isn't bothersome, after all, my friend knows about my diabetes so it's nothing new. (57, W, T2)	153
	Benefits as justification of intrusiveness	The participant justifies the intrusiveness, burden or other negative aspects of adopting digital monitoring, by its potential benefits	The good would outweigh the inconvenience. (W, 70, T1) Just like with any other type of investment, if the benefits are more than the drawbacks, we'll go for it. (M, 87, T2)	11
	Will get used to it	Digital monitoring is something that can be learnt with time and effort until it becomes a habit	It would be a habit that I would have to get used to, and then it would become second nature. (W, 53, T2) At first it would be a bit destabilizing, but that is normal; everything new that we introduce in diabetes management is a bit disruptive at the beginning. (W, 57, T2)	14
	Democratization of diabetes	This refers to the monitoring as a "trigger" that opens the subject of diabetes for discussion with others. It includes comments on the existing openness around diabetes, which makes the use of devices acceptable for the participant.	I've recently been more out in the open about my diabetes, and use monitoring and treatment as opportunities to explain diabetes and how I live with it. (W, 52, T2) It might give friends and family a deeper understanding (W, 44, T1)	5

Themes	Codes	Definition	Examples	Prevalence (n of responses)
	Does not own a smartphone	The participant does not have a smartphone on which to use the monitoring apps.	I do not have a phone. Cannot afford one. (M, 61, T2)	8
	Inability to adhere to physical activity	Physical limitations prevent the participant from engaging in physical activity	[The] fitness/activity app [is intrusive]. I have a pre-existing physical health condition apart from diabetes which complicates activity. (M, 50, T2) Not everyone is an athlete and very few doctors actually understand what it's like to live with chronic terrible pain from things like neuropathy [.] (W, 36, T1)	4

Supplemental Figure 1: Participant flow chart

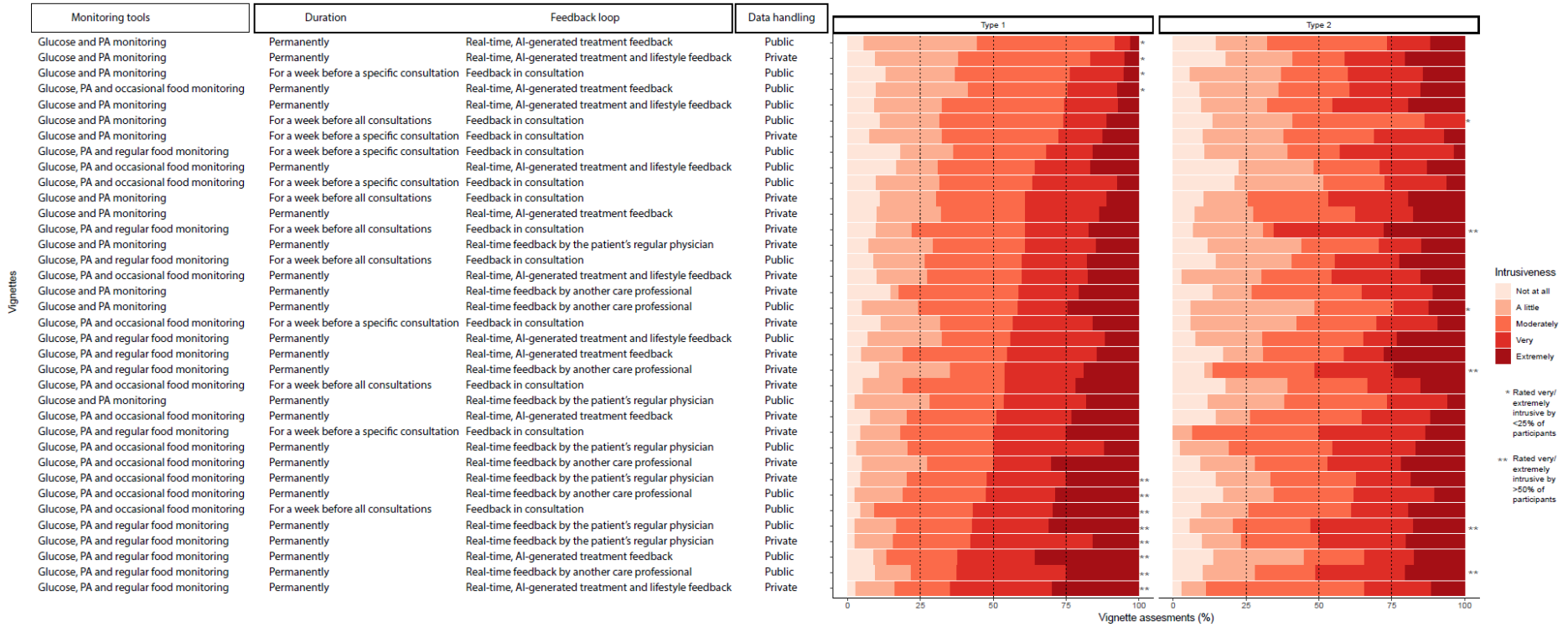


Supplemental Figure 2: Subgroup analysis of intrusiveness by insulin use



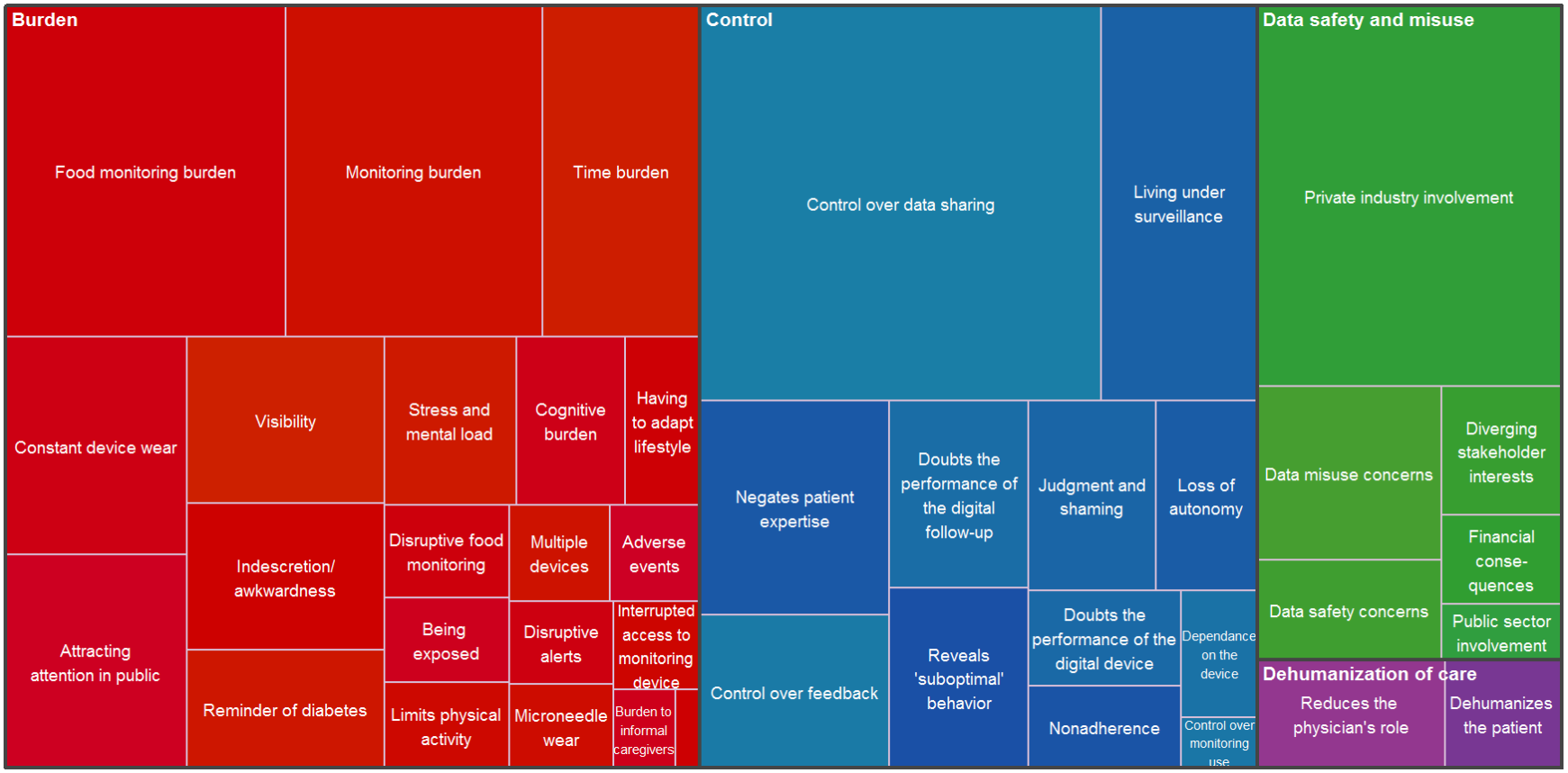
The figure shows intrusiveness by insulin use subgroup. The vignettes are ranked by the proportion of assessments rated very/extremely intrusive (from smallest to largest) for the insulin shot use subgroup. The asterisks mark the vignettes with low and high intrusiveness. There are more vignettes with low intrusiveness (rated very/extremely intrusive by <25% of participants) in the insulin shots subgroup, and more vignettes with high intrusiveness (rated very/extremely intrusive by >50% of participants) in the insulin pump subgroup, compared to the other subgroups.

Supplemental Figure 3: Subgroup analysis of intrusiveness by diabetes type



The figure shows intrusiveness by diabetes type subgroup. The vignettes are ranked by the proportion of assessments rated very/extremely intrusive (from smallest to largest) for the type 1 diabetes subgroup. The asterisks mark the vignettes with low and high intrusiveness scores.

Supplemental Figure 4: Drivers of intrusiveness reported by participants



The figure presents the findings of the qualitative analysis of 1208 responses to open-ended questions provided by 709 participants. Each color represents one of the 4 themes identified (theme title in bold). Each colored rectangle is divided into smaller rectangles, representing individual codes. The size of each rectangle is proportionate to the prevalence of each code and theme (calculated as the number of responses the code appears in). As can be seen in the figure, Burden and Control are the most prevalent aspects identified in the qualitative data.

Annex 2: Supplementary article files for Oikonomidi et al, JAMA Network Open, 2021

eMethods 1: Vignette example

Imagine that your doctor prescribes that you use the diabetes monitoring below, at no additional financial cost to you.

Scenario 1/3:

Digital tools:

- A glucose sensor and an app to monitor your physical activity.
- An app to monitor your food intake. You will have to take pictures of only the meals, snacks or drinks that are unusual to what you ordinarily consume.

Monitoring duration:

- This will be your regular monitoring from now on.

Adapting your treatment:

- Your data will be used to automatically adapt your treatment. This information will appear on your smartphone in real time.
- No regular visits will be required to follow-up on your diabetes, but you will be able to make an appointment with your doctor if you wish to.
- Your doctor will not receive any real-time notifications.

Data handling:

- Your data will be handled by a private organization (an insurance, a pharmaceutical or an informatics company).

1. How intrusive would this diabetes monitoring be to your daily life? *

☐	☐	☐	☐	☐
Not at all	A little	Moderately	Very	Extremely

2. How reassured would this monitoring make you feel? *

☐	☐	☐	☐	☐
Not at all	A little	Moderately	Very	Extremely

3. How effective would this monitoring have to be at reducing the frequency of hypoglycaemic episodes (low glucose levels) for you to choose it over your current way of monitoring? *

☐	☐	☐	☐	☐
It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective

4. How effective would this monitoring have to be at preventing eye complications in the future for you to choose it over your current way of monitoring? *

☐	☐	☐	☐	☐

It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective

* Required responses

eMethods 2: Data collection and piloting

I. Collected data

Participants' perceptions of intrusiveness for each vignette were collected using the question "How intrusive would this monitoring be to your daily life?" (response range "Not at all" to "Extremely"). We collected the following demographic and diabetes-related data: age, sex, education, country, diabetes type, insulin use, number of hypoglycemic episodes in the past month, 3 items from the Problem Areas In Diabetes [PAID] scale on burnout, guilt, and worry about complications, intrusiveness rating of participants' current monitoring, and participants' current use of digital monitoring tools.

II. Piloting

The survey was drafted in English and translated to French by a bilingual author (TO). The translation was compared to the original version by two bilingual French speakers. The survey was pilot-tested with 3 participants (2 women with type 1 diabetes, 1 man with type 2 diabetes).

eMethods 3: Model description

III. Multiple imputation

Data were missing in 418 observations (i.e., vignette assessments) for the following pre-specified candidate predictor variables of the LMM model: number of hypoglycemic episodes in the past 30 days, Problem Areas In Diabetes (PAID) questionnaire items on burnout and worry, and current use of monitoring tools. Because all of these questions were presented in the final page of the survey, we assumed data to be missing not at random (e.g., due to participant fatigue). Data were missing from the variable insulin use for 4 observations owing to a javascript error in the survey website.

We present the characteristics of participants with complete and incomplete data below. We used the mice R package to impute missing data with 30 iterations. The number of hypoglycemic episodes in the past 30 days, and the two PAID questionnaire items were imputed by using predictive means matching. Current use of monitoring tools was imputed by using polytomous regression.

Multiple imputation drew information from the following variables (which were present for all participants): age, sex, country of residence, diabetes type, whether the participant considered their diabetes to be well controlled or not, insulin use, and outcome data (intrusiveness and minimum required efficacy scores). A participant identifier variable was used as the grouping variable to indicate the clustered structure of our data (i.e., several vignettes assessed by the same participant).

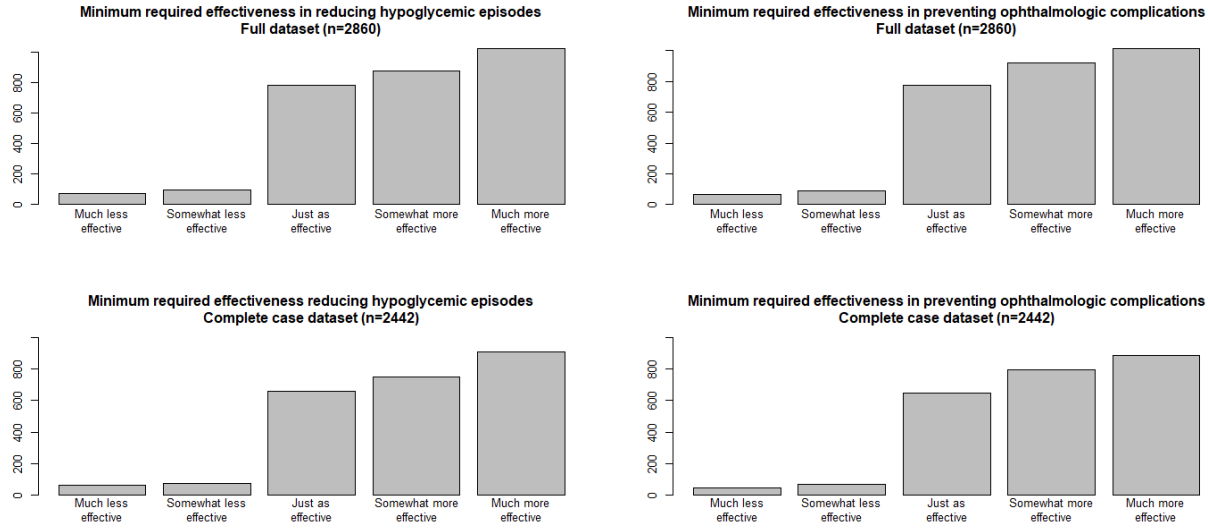
Table: Characteristics of participants with complete and incomplete data

Characteristics	**Complete data (n=814)**	**Incomplete data (n=196)**
Age, median (IQR)	51 [37, 63]	52 [37, 64]
Gender, No. (%)		
Male	311 (38)	83 (42)
Female	471 (58)	101 (52)
Prefers to self-describe	32 (4)	12 (6)
Country of residence, No. (%)		
France	301 (37)	61 (32)
Canada	171 (21)	40 (21)
United States	110 (14)	28 (15)
United Kingdom	86 (11)	22 (11)
Ireland	60 (7)	22 (11)
Other	84 (10)	20 (10)
Post-secondary education	584 (71)	143 (73)
Diabetes type, No. (%)		
Type 1	423 (52)	101 (52)
Type 2	340 (42)	71 (36)

Other	51 (6)	24 (12)
Considers diabetes well-controlled	559 (69)	128 (65)
Uses insulin, No. (%) [a]		
Yes, shots	303 (37)	86 (45)
Yes, pump	272 (33)	59 (31)
No	239 (29)	47 (24)

[a] missing in n=4 of participants with incomplete data

IV. Distribution of the dependent variables



V. Variables entered in the model

All independent variables for both models were selected on the basis of previous publications and clinical experience by the authors.[56,88,89]

The following independent variables were entered in both theory-driven models: vignette factor 1 (monitoring tools, categorical variable with 3 categories), vignette factor 2 (duration/feedback loop, categorical with 6 categories), vignette factor 3 (data handling, binary), intrusiveness (continuous), age (continuous), insulin use (categorical with 3 categories: no insulin, shots, pump), country (categorical with 4 categories: France, United States, Canada, other), number of hypoglycemic episodes in the last 30 days (continuous), self-reported diabetes control (binary variable), PAID item on complications worry (continuous), PAID item on burnout (continuous), and current use of digital monitoring (categorical with 3 categories: participants who neither use nor intend to use monitoring tools in the future, participants who intend to use them or use them irregularly, and participants who use them regularly).

Because the minimum required effectiveness questions are rated with comparison to the patients' current monitoring, the vignette score for intrusiveness was entered in the models in comparison to the participant's current monitoring. For this, we subtracted the intrusiveness score each participant assigned to their current monitoring from the vignette intrusiveness score.

The dependent variables (minimum required effectiveness scores) were handled as ordinal. Higher values indicate higher required effectiveness.

VI. Model fit and selection of predictors

The model was fit in the imputed dataset. Correlations among independent variables were assessed for multi-collinearity. Starting from the theory-driven model specified above, we removed the weakest predictor based on its coefficient and refit the model. If this step provided improved fit (based on the Akaike information criteria [AIC], smaller values implying a better model fit), the next weakest predictor was removed, until no further improvement in AIC was achieved.

The following predictors were removed to arrive to the final model for minimum required efficacy in reducing hypoglycemic episodes: age, number of hypoglycemic episodes, current regular use of monitoring tools, 2 levels of the second vignette factor (permanently, with real-time, AI-generated treatment and lifestyle feedback, monitoring for a week before all consultations with feedback in consultation), the third vignette factor (public-sector data handling), male gender, and self-reported diabetes control (theory-driven model AIC = 6206, final model AIC = 6195).

The following predictors were removed to arrive to the final model for minimum required efficacy in preventing ophthalmologic complications: age, number of hypoglycemic episodes, current regular use of monitoring tools, 3 levels of the second vignette factor (permanently, with real-time, AI-generated treatment feedback; monitoring permanently, with real-time, AI-generated treatment and lifestyle feedback; monitoring for a week before all consultations with feedback in consultation), the third vignette factor (public-sector data handling), the PAID item on burnout, male gender, other/self-reported gender, and self-reported diabetes control (theory-driven model AIC = 5942, final model AIC = 5863).

R^2 was estimated for the models by using Nagelkerke's method.

eTable 1: Minimum required effectiveness per vignette.

Vignette	n	Minimum required effectiveness for reducing hypoglycemic episodes (%)					Minimum required effectiveness for preventing ophthalmologic complications (%)				
		It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective	It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective
Glucose and PA monitoring, for a week before a specific consultation with feedback in consultation, and public-sector data handling	80	2 (2)	3 (4)	22 (28)	29 (36)	24 (30)	3 (4)	1 (1)	24 (30)	23 (29)	29 (36)
Glucose and PA monitoring, for a week before a specific consultation with feedback in consultation, and private-sector data handling	78	4 (5)	1 (1)	23 (29)	21 (27)	29 (37)	3 (4)	2 (3)	23 (29)	23 (29)	27 (35)
Glucose and PA monitoring, for a week before all consultations with feedback in consultation, and public-sector data handling	76	2 (3)	2 (3)	21 (28)	20 (26)	31 (41)	2 (3)	2 (3)	20 (26)	25 (33)	27 (36)
Glucose and PA monitoring, for a week before all consultations with feedback in consultation, and private-sector data handling	86	2 (2)	3 (3)	28 (33)	31 (36)	22 (26)	4 (5)	0 (0)	26 (30)	30 (35)	26 (30)

Vignette	n	Minimum required effectiveness for reducing hypoglycemic episodes (%)					Minimum required effectiveness for preventing ophthalmologic complications (%)				
		It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective	It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective
Glucose and PA monitoring, permanently with real-time feedback by the patient's regular physician, and public-sector data handling	79	3 (4)	4 (5)	20 (25)	28 (35)	24 (30)	2 (3)	3 (4)	24 (30)	23 (29)	27 (34)
Glucose and PA monitoring, permanently with real-time feedback by the patient's regular physician, and private-sector data handling	79	1 (1)	0 (0)	19 (24)	33 (42)	26 (33)	0 (0)	1 (1)	22 (28)	32 (41)	24 (30)
Glucose and PA monitoring, permanently with real-time feedback by another CP, and public-sector data handling	78	3 (4)	2 (3)	24 (31)	27 (35)	22 (28)	3 (4)	2 (3)	21 (27)	32 (41)	20 (26)
Glucose and PA monitoring, permanently with real-time feedback by another CP, and private-sector data handling	78	2 (3)	3 (4)	18 (23)	24 (31)	31 (40)	0 (0)	3 (4)	21 (27)	23 (29)	31 (40)
Glucose and PA monitoring, permanently with real-time, AI-generated treatment	78	2 (3)	1 (1)	21 (27)	33 (42)	21 (27)	2 (3)	2 (3)	20 (26)	32 (41)	22 (28)

Vignette	n	Minimum required effectiveness for reducing hypoglycemic episodes (%)					Minimum required effectiveness for preventing ophthalmologic complications (%)				
		It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective	It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective
feedback, and public-sector data handling											
Glucose and PA monitoring, permanently with real-time, AI-generated treatment feedback, and private-sector data handling	108	1 (1)	3 (3)	36 (33)	25 (23)	43 (40)	0 (0)	0 (0)	36 (33)	31 (29)	41 (38)
Glucose and PA monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback, and public-sector data handling	80	2 (2)	2 (2)	33 (41)	24 (30)	19 (24)	1 (1)	3 (4)	30 (38)	25 (31)	21 (26)
Glucose and PA monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback, and private-sector data handling	90	1 (1)	2 (2)	31 (34)	22 (24)	34 (38)	0 (0)	3 (3)	32 (36)	23 (26)	32 (36)
Glucose, PA and regular food monitoring, for a week before a specific consultation with feedback in consultation, and public-sector data handling	78	2 (3)	2 (3)	30 (38)	23 (29)	21 (27)	1 (1)	2 (3)	26 (33)	25 (32)	24 (31)

Vignette	n	Minimum required effectiveness for reducing hypoglycemic episodes (%)					Minimum required effectiveness for preventing ophthalmologic complications (%)				
		It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective	It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective
Glucose, PA and regular food monitoring, for a week before a specific consultation with feedback in consultation, and private-sector data handling	77	1 (1)	4 (5)	18 (23)	26 (34)	28 (36)	1 (1)	4 (5)	23 (30)	26 (34)	23 (30)
Glucose, PA and regular food monitoring, for a week before all consultations with feedback in consultation, and public-sector data handling	78	2 (3)	1 (1)	27 (35)	23 (29)	25 (32)	1 (1)	3 (4)	22 (28)	25 (32)	27 (35)
Glucose, PA and regular food monitoring, for a week before all consultations with feedback in consultation, and private-sector data handling	76	4 (5)	0 (0)	17 (22)	24 (32)	31 (41)	2 (3)	0 (0)	16 (21)	22 (29)	36 (47)
Glucose, PA and regular food monitoring, permanently with real-time feedback by the patient’s regular physician, and public-sector data handling	79	1 (1)	6 (8)	19 (24)	22 (28)	31 (39)	2 (3)	3 (4)	22 (28)	22 (28)	30 (38)

Vignette	n	Minimum required effectiveness for reducing hypoglycemic episodes (%)					Minimum required effectiveness for preventing ophthalmologic complications (%)				
		It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective	It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective
Glucose, PA and regular food monitoring, permanently with real-time feedback by the patient's regular physician, and private-sector data handling	77	1 (1)	3 (4)	21 (27)	18 (23)	34 (44)	2 (3)	1 (1)	21 (27)	18 (23)	35 (45)
Glucose, PA and regular food monitoring, permanently with real-time feedback by another CP, and public-sector data handling	77	2 (3)	3 (4)	22 (29)	17 (22)	33 (43)	0 (0)	2 (3)	22 (29)	22 (29)	31 (40)
Glucose, PA and regular food monitoring, permanently with real-time feedback by another CP, and private-sector data handling	77	3 (4)	2 (3)	19 (25)	22 (29)	31 (40)	2 (3)	3 (4)	20 (26)	24 (31)	28 (36)
Glucose, PA and regular food monitoring, permanently with real-time, AI-generated treatment feedback, and public-sector data handling	78	1 (1)	1 (1)	19 (24)	15 (19)	42 (54)	2 (3)	2 (3)	16 (21)	24 (31)	34 (44)

Vignette	n	Minimum required effectiveness for reducing hypoglycemic episodes (%)					Minimum required effectiveness for preventing ophthalmologic complications (%)				
		It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective	It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective
Glucose, PA and regular food monitoring, permanently with real-time, AI-generated treatment feedback, and private-sector data handling	79	3 (4)	1 (1)	21 (27)	28 (35)	26 (33)	3 (4)	1 (1)	23 (29)	32 (41)	20 (25)
Glucose, PA and regular food monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback, and public-sector data handling	78	3 (4)	4 (5)	26 (33)	23 (29)	22 (28)	3 (4)	3 (4)	22 (28)	28 (36)	22 (28)
Glucose, PA and regular food monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback, and private-sector data handling	79	3 (4)	4 (5)	20 (25)	24 (30)	28 (35)	3 (4)	2 (3)	22 (28)	22 (28)	30 (38)
Glucose, PA and occasional food monitoring, for a week before a specific consultation with feedback in consultation,	80	1 (1)	6 (8)	20 (25)	29 (36)	24 (30)	1 (1)	6 (8)	18 (22)	34 (42)	21 (26)

Vignette	n	Minimum required effectiveness for reducing hypoglycemic episodes (%)					Minimum required effectiveness for preventing ophthalmologic complications (%)				
		It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective	It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective
and public-sector data handling											
Glucose, PA and occasional food monitoring, for a week before a specific consultation with feedback in consultation, and private-sector data handling	78	1 (1)	6 (8)	16 (21)	28 (36)	27 (35)	2 (3)	5 (6)	18 (23)	21 (27)	32 (41)
Glucose, PA and occasional food monitoring, for a week before all consultations with feedback in consultation, and public-sector data handling	77	2 (3)	3 (4)	18 (23)	22 (29)	32 (42)	4 (5)	2 (3)	15 (19)	24 (31)	32 (42)
Glucose, PA and occasional food monitoring, for a week before all consultations with feedback in consultation, and private-sector data handling	77	1 (1)	2 (3)	23 (30)	22 (29)	29 (38)	1 (1)	0 (0)	19 (25)	28 (36)	29 (38)
Glucose, PA and occasional food monitoring, permanently with real-time feedback by	79	1 (1)	1 (1)	18 (23)	21 (27)	38 (48)	0 (0)	1 (1)	14 (18)	29 (37)	35 (44)

Vignette	n	Minimum required effectiveness for reducing hypoglycemic episodes (%)					Minimum required effectiveness for preventing ophthalmologic complications (%)				
		It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective	It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective
their regular physician, and public-sector data handling											
Glucose, PA and occasional food monitoring, permanently with real-time feedback by their regular physician, and private-sector data handling	79	1 (1)	6 (8)	20 (25)	21 (27)	31 (39)	1 (1)	5 (6)	24 (30)	23 (29)	26 (33)
Glucose, PA and occasional food monitoring, permanently with real-time feedback by another CP, and public-sector data handling	77	2 (3)	5 (6)	14 (18)	28 (36)	28 (36)	1 (1)	3 (4)	12 (16)	35 (45)	26 (34)
Glucose, PA and occasional food monitoring, permanently with real-time feedback by another CP, and private-sector data handling	77	4 (5)	0 (0)	21 (27)	20 (26)	32 (42)	3 (4)	1 (1)	18 (23)	24 (31)	31 (40)
Glucose, PA and occasional food monitoring, permanently with real-time, AI-generated treatment feedback, and public-sector data handling	78	3 (4)	5 (6)	23 (29)	26 (33)	21 (27)	2 (3)	3 (4)	28 (36)	20 (26)	25 (32)

Vignette	n	Minimum required effectiveness for reducing hypoglycemic episodes (%)					Minimum required effectiveness for preventing ophthalmologic complications (%)				
		It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective	It could be much less effective	It could be somewhat less effective	It would have to be just as effective	It would have to be somewhat more effective	It would have to be much more effective
Glucose, PA and occasional food monitoring, permanently with real-time, AI-generated treatment feedback, and private-sector data handling	79	2 (3)	2 (3)	18 (23)	24 (30)	33 (42)	2 (3)	3 (4)	15 (19)	24 (30)	35 (44)
Glucose, PA and occasional food monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback, and public-sector data handling	79	2 (3)	1 (1)	14 (18)	30 (38)	32 (41)	2 (3)	4 (5)	18 (23)	27 (34)	28 (35)
Glucose, PA and occasional food monitoring, permanently with real-time, AI-generated treatment and lifestyle feedback, and private-sector data handling	77	5 (6)	5 (6)	24 (31)	23 (30)	20 (26)	4 (5)	6 (8)	20 (26)	21 (27)	26 (34)

PA, physical activity; CP, care professional; AI, artificial intelligence

eTable 2. Cumulative link mixed model for the minimum required efficacy outcomes in the complete-case dataset (n=2442).

	Minimum required effectiveness					
	Reducing hypoglycemic episodes [a]			**Preventing ophthalmologic complications [b]**		
Predictors	**Estimate (SE)**	**OR (95% CI)**	**P**	**Estimate (SE)**	**OR (95% CI)**	**P**
Intercept: Much less | Somewhat less	-5.5 (0.47)	0.00 (0.00–0.01)	<0.001	-7.6 (0.57)	0.00 (0.00–0.00)	<0.001
Intercept: Somewhat less | Just as	-3.91 (0.44)	0.02 (0.01–0.05)	<0.001	-5.39 (0.51)	0.00 (0.00–0.01)	<0.001
Intercept: Just as | Somewhat more	0.19 (0.42)	1.20 (0.53–2.73)	0.66	-0.61 (0.47)	0.54 (0.21–1.38)	0.20
Intercept: Somewhat more | Much more	3.01 (0.43)	20.32 (8.83–46.75)	<0.001	2.75 (0.48)	15.65 (6.12–40.04)	<0.001
Vignette-level predictors						
Monitoring tools (reference category: glucose and PA)						
Glucose, PA and regular food monitoring	0.39 (0.13)	1.48 (1.14–1.92)	0.003	0.3 (0.14)	1.35 (1.03–1.77)	0.03
Glucose, PA and occasional food monitoring	0.47 (0.13)	1.60 (1.24–2.08)	<0.001	0.35 (0.14)	1.42 (1.08–1.87)	0.01
Duration/feedback loop (ref. cat.: For a week before a specific consultation, with						

feedback in consultation)						
Permanently, with real-time feedback by the patient's regular physician	0.26 (0.16)	1.30 (0.95–1.77)	0.10	0.21 (0.15)	1.23 (0.91–1.67)	0.17
Permanently, with real-time feedback by another care professional	0.41 (0.16)	1.51 (1.09–2.07)	0.01	0.47 (0.16)	1.60 (1.18–2.18)	0.003
Permanently, with real-time, artificial intelligence-generated treatment feedback [c]	0.38 (0.16)	1.46 (1.07–1.98)	0.02			
Permanently, with real-time, artificial intelligence-generated treatment and lifestyle feedback [c]	0.14 (0.16)	1.15 (0.84–1.56)	0.39			
Intrusiveness rating	0.38 (0.06)	1.47 (1.30–1.65)	<0.001	0.44 (0.06)	1.55 (1.37–1.76)	<0.001
Participant characteristics						
Intends to use monitoring tools	-0.26 (0.33)	0.77 (0.40–1.47)	0.43	-0.29 (0.38)	0.75 (0.36–1.57)	0.44

for health or wellbeing purposes, or uses them irregularly (reference category: does not use them and does not intend to)						
Feeling "burned out" by the constant effort needed to manage diabetes (PAID questionnaire item) [c]	0.15 (0.13)	1.16 (0.90–1.50)	0.25			
Worrying about the future and the possibility of serious complications (PAID questionnaire item)	0.23 (0.14)	1.26 (0.96–1.66	0.09	0.47 (0.13)	1.60 (1.25–2.05)	<0.001
Insulin use (ref. cat.: no insulin use)						
Insulin shots	0.72 (0.31)	2.05 (1.12–3.76)	0.02	0.39 (0.35)	1.48 (0.74–2.96)	0.27
Insulin pump	1.09 (0.33)	2.99 (1.57–5.68)	0.001	0.69 (0.37)	1.99 (0.96–4.09)	0.06
Country of residence (ref. cat.: France)						
Countries other than France, United States and Canada	-0.72 (0.31)	0.49 (0.27–0.89)	0.02	-1.33 (0.36)	0.27 (0.13–0.53)	<0.001

United States	-0.3 (0.39)	0.74 (0.34–1.59)	0.44	-1.18 (0.45)	0.31 (0.13–0.74)	0.008
Canada	-0.07 (0.34)	0.94 (0.48–1.82)	0.85	-0.36 (0.39)	0.70 (0.32–1.49)	0.35
Gender: Prefers to self-describe (ref. cat.: woman)[c]	0.51 (0.63)	1.67 (0.48–5.72)	0.42			

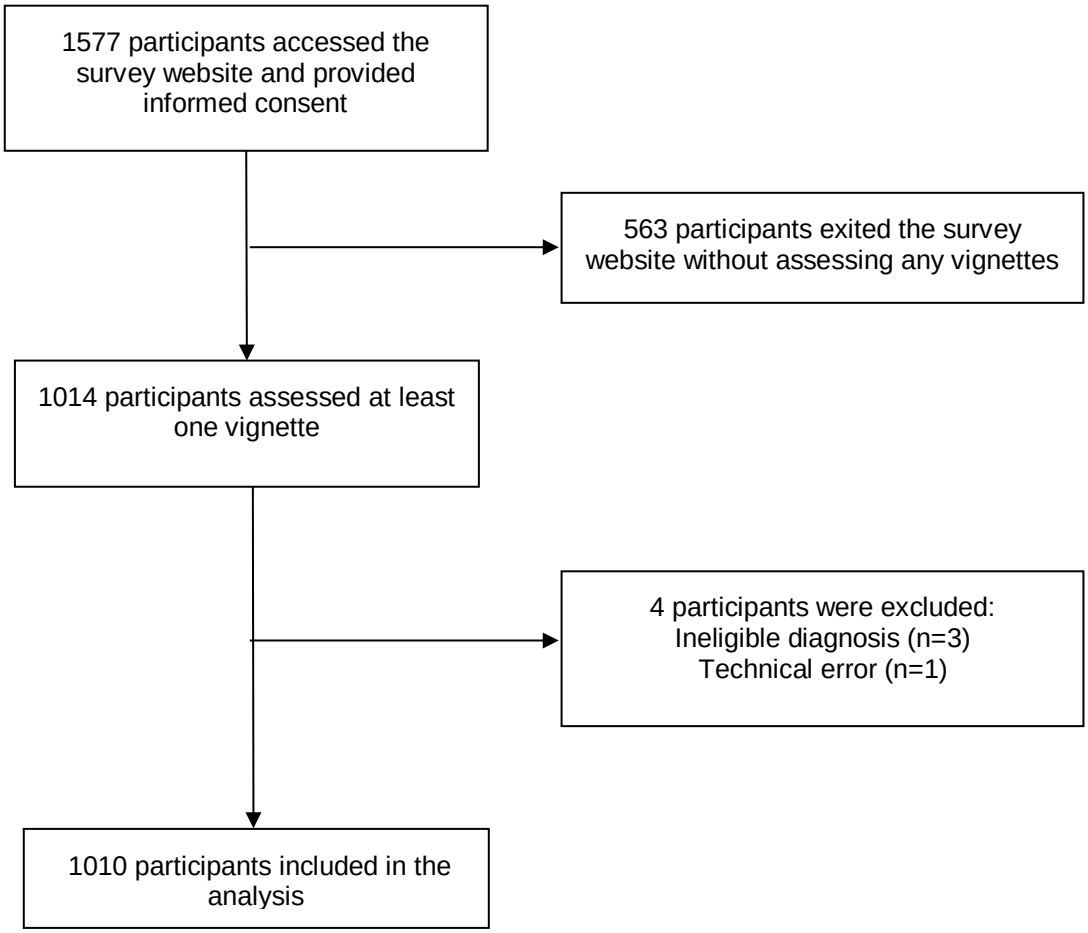
SE, standard error; OR, odds ratio; 95% CI, 95% confidence interval

[a] AIC = 5188, pseudo-R2 = 0.06 (estimated for the model vs the null using Nagelkerke's method).

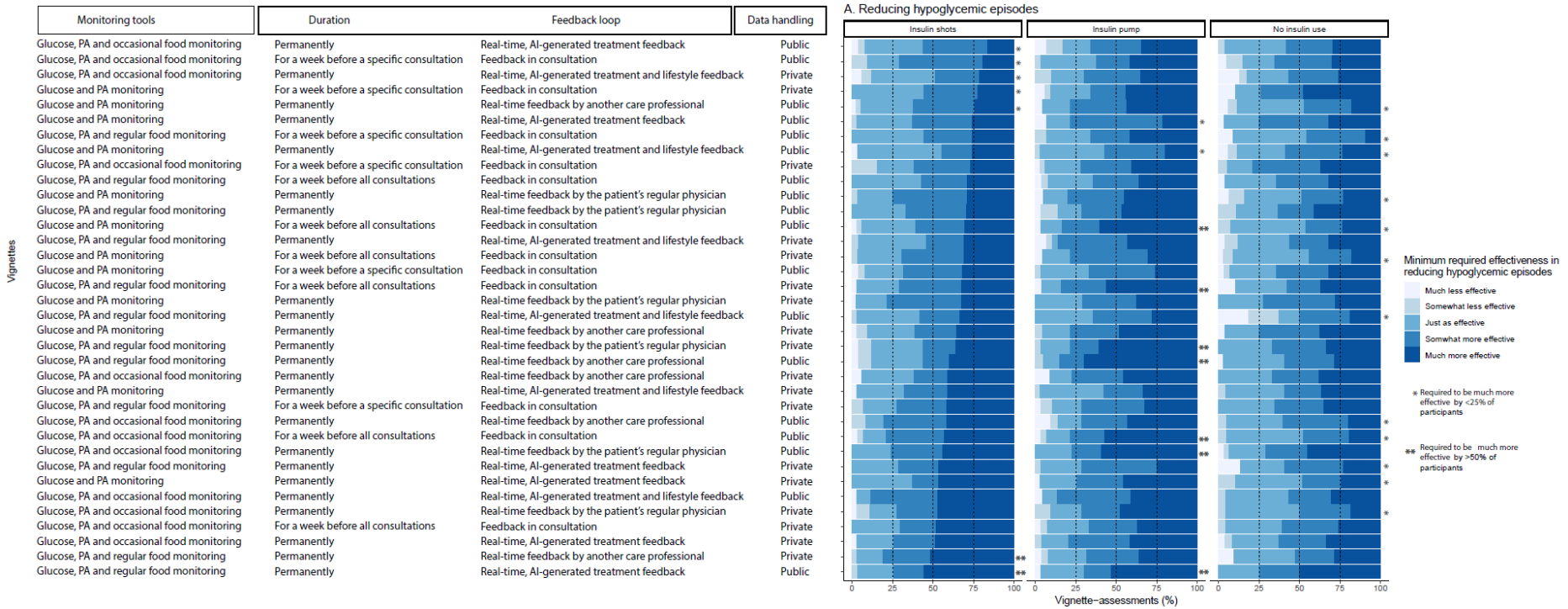
[b] AIC = 4861, pseudo-R2 = 0.07 (estimated for the model vs the null using Nagelkerke's method).

[c] This variable was not included in the final model for minimum required effectiveness in preventing ophthalmologic complications

eFigure 1: Participant flow chart

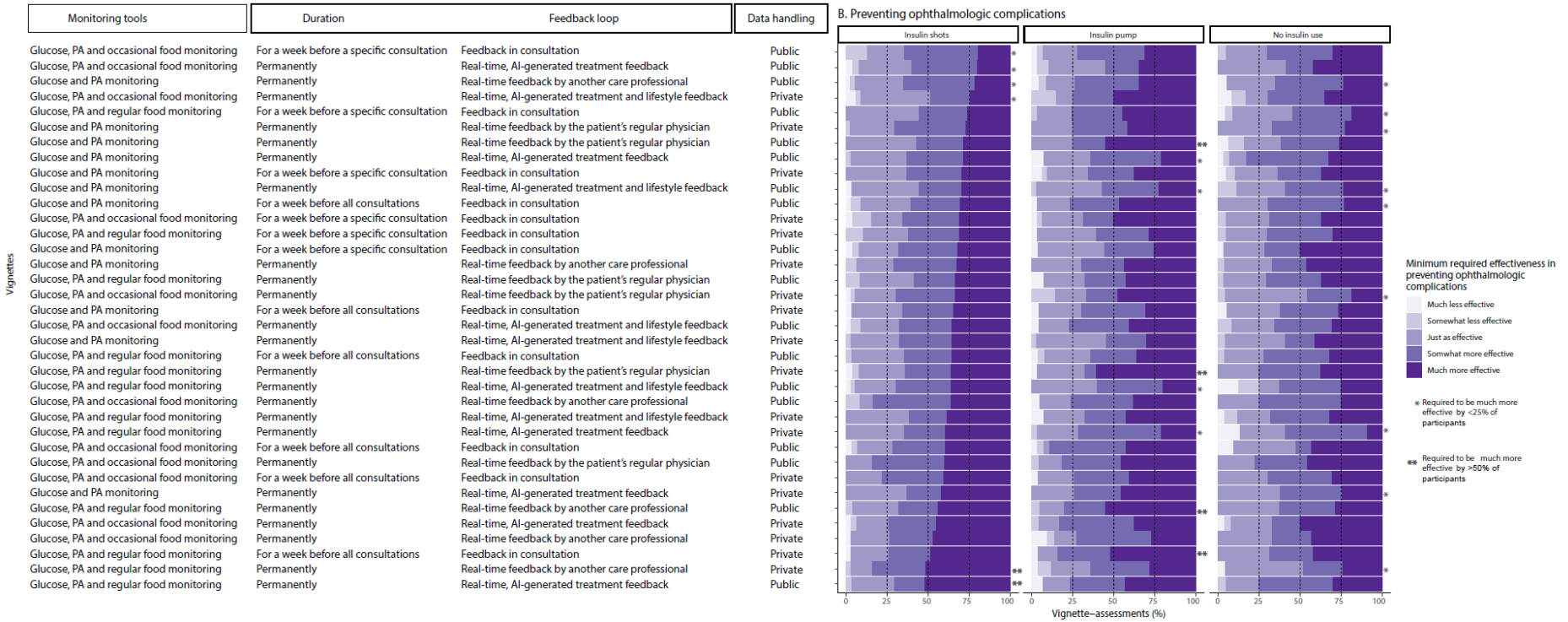


eFigure 2: Subgroup analysis by insulin use (reducing hypoglycemic episodes)



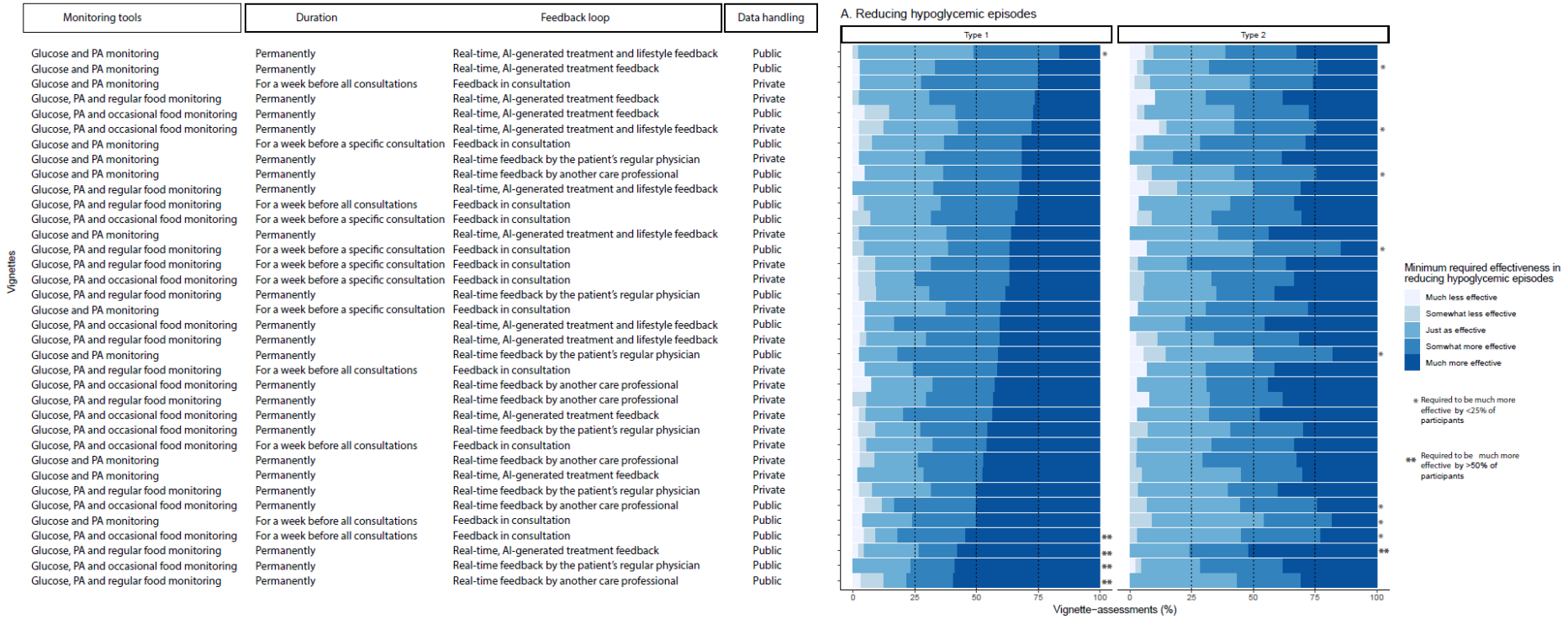
The figure shows the minimum required effectiveness of remote digital monitoring (RDM) in reducing hypoglycemic episodes by insulin use subgroup. The vignettes are ranked by the proportion of vignette assessments requiring that the vignette RDM be much more effective than the participant's current monitoring for the subgroup of insulin shots. The asterisks show vignettes with high and low minimum required effectiveness. There were 5 vignettes with low minimum required effectiveness for participants who use insulin shots, 2 for participants who use an insulin pump and 12 for those who use no insulin. There were 2 vignettes with high minimum required effectiveness for participants who use insulin shots, 7 for participants who use an insulin pump and none for those who use no insulin.

eFigure 3: Subgroup analysis by insulin use (preventing ophthalmologic complications)



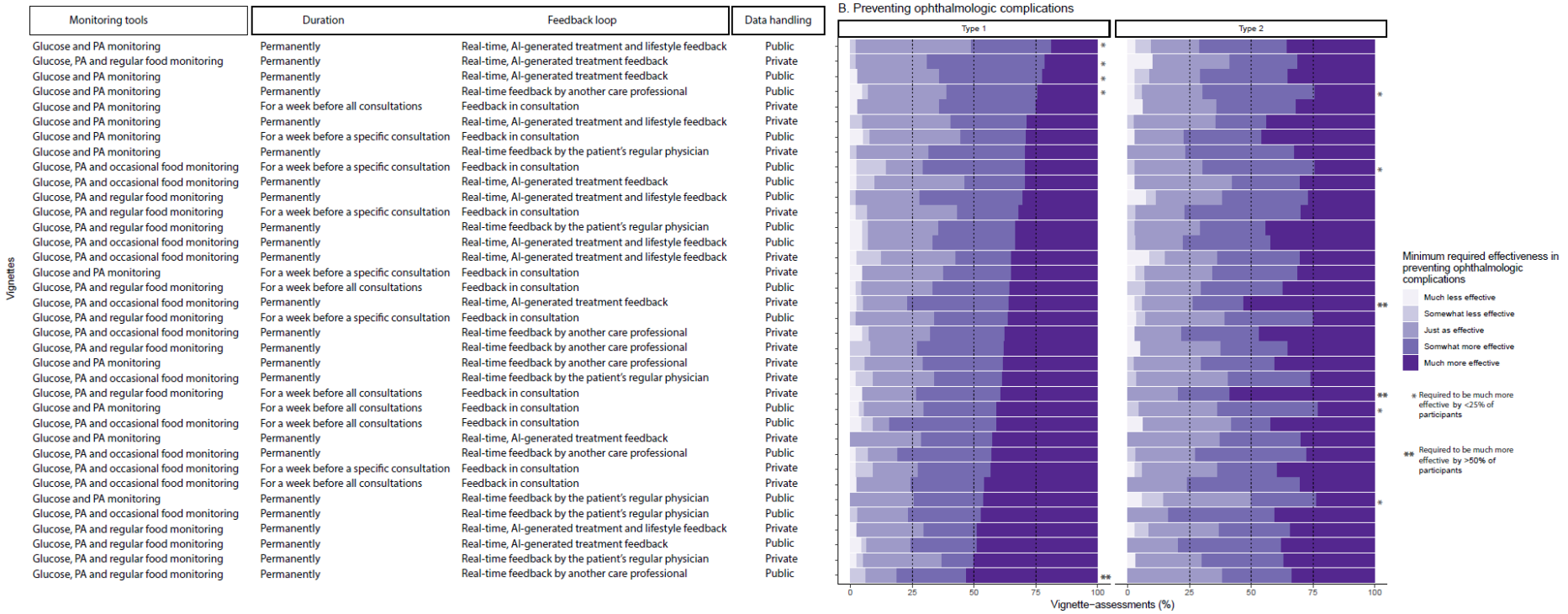
The figure shows the minimum required effectiveness of remote digital monitoring (RDM) in preventing ophthalmologic complications by insulin use subgroup. The vignettes are ranked by the proportion of vignette assessments requiring that the vignette RDM be much more effective than the participant's current monitoring for the insulin shots subgroup. The asterisks show vignettes with high and low minimum required effectiveness. There were 4 vignettes with low minimum required effectiveness for participants who use insulin shots, 4 for participants who use an insulin pump and 9 for those who use no insulin. There were 2 vignettes with high minimum required effectiveness for participants who use insulin shots, 4 for participants who use an insulin pump and none for those who use no insulin.

eFigure 4: Subgroup analysis by diabetes type (reducing hypoglycemic episodes)



The figure shows the minimum required effectiveness of remote digital monitoring (RDM) in reducing hypoglycemic episodes by diabetes type subgroup. The vignettes are ranked by the proportion of vignette assessments requiring that the vignette RDM be much more effective than the participant's current monitoring for the subgroup of participants with type 1 diabetes. The asterisks show vignettes with high and low minimum required effectiveness. There was 1 vignette with low minimum required effectiveness for participants who had type 1 diabetes, and 8 for participants who had type 2 diabetes. There were 4 vignettes with high minimum required effectiveness for participants who had type 1 diabetes, and 1 for participants who had type 2 diabetes.

eFigure 5: Subgroup analysis by diabetes type (preventing ophthalmologic complications)



The figure shows the minimum required effectiveness of remote digital monitoring (RDM) by diabetes type subgroup, for preventing ophthalmologic complications. The vignettes are ranked by the proportion of vignette assessments requiring that the vignette RDM be much more effective than the participant's current monitoring for the subgroup of participants with type 1 diabetes. The asterisks show vignettes with low and high minimum required effectiveness. There are more outlier vignettes with low minimum required effectiveness in the type 2 subgroup. There were 4 vignettes with low minimum required effectiveness for both participants with type 1 and type 2 diabetes (see Supplemental Figure 7 for vignette description). There was 1 vignette with high minimum required effectiveness for participants who had type 1 diabetes, and 2 for participants who had type 2 diabetes.

Annex 3: Supplementary article files for Oikonomidi et al, JAMA Network Open (in press)

eMethods 1: Survey (English translation)

--- Home page ---

During the COVID-19 pandemic, the ways in which patients access health care services changed and new, technology-based services emerged, aiming to limit the spread of the virus. **These changes may affect the way we access health care even after the end of the COVID-19 pandemic.**

For example, a hospital that replaced in-person consultations with teleconsultations in 2020 may decide to offer **both types of consultations to their patients** after the end of the pandemic.

This survey aims to understand how we can adapt regular care (that is, the way you used to receive care before the pandemic started), by adopting components from the care models applied during the pandemic. First, we will present you a list of things that changed in health care delivery during the pandemic in a short video. You will then be asked questions about how we could best combine these new care components with regular care in order to create the ideal care model for you.

Participation in this survey takes 15 to 20 minutes.

---Page 1 ---

Your vision of the future of health care

In the video below, we present examples of changes in health care delivery that took place during the pandemic. To see a written list of these changes, click here: https://inspire-compare.fr/compare/Window_after_interviews.pdf

[embedded video https://youtu.be/GbfOYypjmn0]

Imagine that all these innovations put in place during the pandemic remain available to you, in the long-term, after the end of the pandemic. How could we integrate these innovations (if at all) in the care of patients with chronic illnesses in order to improve health care after the end of the pandemic?

The innovations presented here are only a few of the modifications in health care delivery experienced by patients during the pandemic. Do not hesitate to express your own ideas in your answers to the questions below. Do not hesitate to give detailed responses so that we can better understand your point of view.

Imagine the ideal care for yourself, in the long term. By ideal care we mean the care you wish to receive as a patient, according to your own criteria (e.g., more effective, less burdensome, etc.).

1. In which ways would it be **different** from the regular care you received before the pandemic? *

2. How would the innovations in health care delivery, implemented during the pandemic and presented above help you obtain this ideal care? *

--- Page 2 ---

Consultations with your physician

In the following pages of this survey, we describe 3 changes in health care delivery experienced by many patients during the pandemic.

The following questions may help you generate more ideas about the future of health care. In this case, do not hesitate to **return to the previous page of the survey and modify your responses.**

During the pandemic, many patients replaced **in-person consultations** with their physician with **teleconsultations** (e.g., by phone or video call).

a. Have you used teleconsultations in the management of your chronic illness, at least once, **before the pandemic**?*

   ☐ Yes

   ☐ No

b. Did you use teleconsultations in the management of your chronic illness, at least once, **during the pandemic**?*

   ☐ Yes

   ☐ No

Imagine that after the end of the pandemic, you could use teleconsultations for the management of your chronic illness. We would like to know what **the ideal balance** would be for you, between teleconsultations and in-person consultations.

c. For what proportion of your future consultations, would you choose to use **teleconsultations**?*

Your remaining consultations would be in-person.

[0 to 100% sliding scale, labelled: “None of my consultations” to “All of my consultations”]

d. Please use the text box below to explain why you chose this response. [text box]

---Page 3 ---

Managing new or worsening symptoms

During the pandemic, many patients used interactive websites called symptom checkers, to quickly receive advice for new or worsening symptoms they experienced, instead of contacting their physician.

A symptom checker is a website that asks questions about your symptoms and, using an algorithm, gives you advice on how to best manage them (e.g., self-management advice, recommendation to go to the E.R. or call your regular physician, etc.)

a. Had you used a symptom checker at least once **before the pandemic**?*

   ☐ Yes

☐ No

b. Did you use a symptom checker at least once, **during the pandemic** (including to identify if the symptoms you experienced could be due to a COVID-19 infection)?*

☐ Yes

☐ No

Imagine that after the end of the pandemic, you could use symptom checkers to receive advice at instances of new or worsening symptoms of your illness, instead of having to contact your physician.

c. For what proportion of these instances would you choose to use **a symptom checker**?*

In the remaining instances you would contact your physician.

[0 to 100% sliding scale, labelled: "None of these instances" to "All of these instances"]

d. Please use the text box below to explain why you chose this response. [text box]

---Page 4 ---

Monitoring your health at home

The questions below concern only patients who use self-monitoring tools to monitor and manage their condition (e.g., a glucose meter, a blood pressure cuff, a symptom diary, etc). Do you use such monitoring tools? *

☐ Yes

☐ No

[Note: the following 2 questions were presented only to participants who selected "Yes" in the above question.]

During the pandemic, some patients shared the data collected using self-monitoring tools with their physician, remotely and outside of regular consultations (e.g., by giving their physician direct access to their dashboard, by sending the data via e-mail). This enabled their physician to adjust their treatment outside of consultations.

a. Had you shared monitoring data remotely with your physician at least once **before the pandemic**? *

☐ Yes

☐ No

b. Did you share monitoring data remotely with your physician at least once **during the pandemic?** *

☐ Yes

☐ No

Imagine that after the end of the pandemic, you could share data collected by using a self-monitoring tool with your physician, remotely, when you need a medical opinion on your data. This would enable your physician to adjust your treatment outside of regular consultations.

c. For what proportion of these instances would you choose to share your data with your physician remotely, outside of consultations? *

In the remaining instances you would share your data with your physician in consultation.

[0 to 100% sliding scale, labelled: “None of these instances” to “All of these instances”]

d. Please use the text box below to explain why you chose this response. [text box]

---Page 5 ---

Finally, of the options below, please select **all that apply to** you:*

- ☐ I am a health care professional (e.g., physician, nurse, physiotherapist, etc.)
- ☐ I am a caregiver to an ill family member or friend
- ☐ I am neither a health care professional nor a caregiver

* Starred questions require a response to continue to the next page of the survey.

eMethods 2: Literature review

We followed standard literature review methods to identify alternative care modalities implemented during the COVID-19 pandemic.

First, we searched Pubmed on December 2, 2020 using the following search strategy:

#7	#4 AND #5 AND #6
#6	#1 OR #2 OR #3
#5	"systematic review"[Publication Type] OR "systematic review"[Text Word]
#4	"covid 19"[Title/Abstract] OR "covid19*"[Title/Abstract] OR "covid 19"[Title/Abstract] OR "SARS CoV-2"[Title/Abstract] OR "2019nCoV"[Title/Abstract] OR "2019 ncov"[Title/Abstract] OR "nCoV2019"[Title/Abstract] OR "nCoV-2019"[Title/Abstract] OR "coronavir*"[Title/Abstract] OR "corona-virus"[Title/Abstract] OR "coronovir*"[Title/Abstract] OR "corono-virus"[Title/Abstract] OR "corona-virus"[Title/Abstract] OR "corono-virus"[Title/Abstract] OR "betacoronavir*"[Title/Abstract] OR "beta-coronavirus"[Title/Abstract] OR "beta-coronavirus"[Title/Abstract] OR "2019 ncov"[Title/Abstract] OR "n-cov"[Title/Abstract] OR "ncov*"[Title/Abstract] OR (("virus"[Title/Abstract] OR "viruses"[Title/Abstract] OR "viral"[Title/Abstract]) AND "wuhan*"[Title/Abstract]) OR (("virus"[Title/Abstract] OR "viruses"[Title/Abstract] OR "viral"[Title/Abstract]) AND "covid*"[Title/Abstract]) OR "COVID-19 diagnostic testing"[Supplementary Concept] OR "covid 19"[Supplementary Concept] OR "severe acute respiratory syndrome coronavirus 2"[Supplementary Concept]
#3	("reorganization"[Title/Abstract] OR "remote*"[Title/Abstract] OR "distance"[Title/Abstract] OR "video*"[Title/Abstract]) AND ("care"[Title/Abstract] OR "healthcare"[Title/Abstract] OR "health care"[Title/Abstract] OR "consult*"[Title/Abstract] OR "appointment*"[Title/Abstract])
#2	("monitoring"[Title/Abstract] OR "surveillance"[Title/Abstract]) AND "remote*"[Title/Abstract])
#1	("social media"[Title/Abstract] OR "Facebook"[Title/Abstract] OR "Whatsapp"[Title/Abstract] OR "Youtube"[Title/Abstract] OR "Skype"[Title/Abstract] OR "Twitter"[Title/Abstract] OR "WeChat"[Title/Abstract] OR "Weibo"[Title/Abstract] OR "SMS"[Title/Abstract] OR "short messaging service"[Title/Abstract] OR "text messages"[Title/Abstract] OR "text messaging"[Title/Abstract] OR "virtual"[Title/Abstract] OR "online"[Title/Abstract] OR "web based"[Title/Abstract] OR "web delivered"[Title/Abstract] OR "web platform"[Title/Abstract] OR "smartphone"[Title/Abstract] OR "internet"[Title/Abstract] OR "wearable*"[Title/Abstract] OR "telephone*"[Title/Abstract] OR "phone*"[Title/Abstract] OR "digital"[Title/Abstract] OR "m health"[Title/Abstract] OR "mhealth"[Title/Abstract] OR "e health"[Title/Abstract] OR "ehealth"[Title/Abstract] OR

	"conversational agent*"[Title/Abstract] OR "chatbot"[Title/Abstract] OR "artificial intelligence"[Title/Abstract] OR "telecare*"[Title/Abstract] OR "telehealth*"[Title/Abstract] OR "telemedicine*"[Title/Abstract] OR "telepsychiatry"[Title/Abstract] OR "telerehabilitation*"[Title/Abstract] OR "tele-care"[Title/Abstract] OR "tele-health"[Title/Abstract] OR "tele-medicine"[Title/Abstract] OR "tele-psychiatry"[Title/Abstract] OR "tele-rehabilitation"[Title/Abstract] OR "technolog*"[Title/Abstract] OR "self triage"[Title/Abstract] OR "symptom checker"[Title/Abstract] OR ("messag*"[Title/Abstract] AND ("platform"[Title/Abstract] OR "software"[Title/Abstract]))

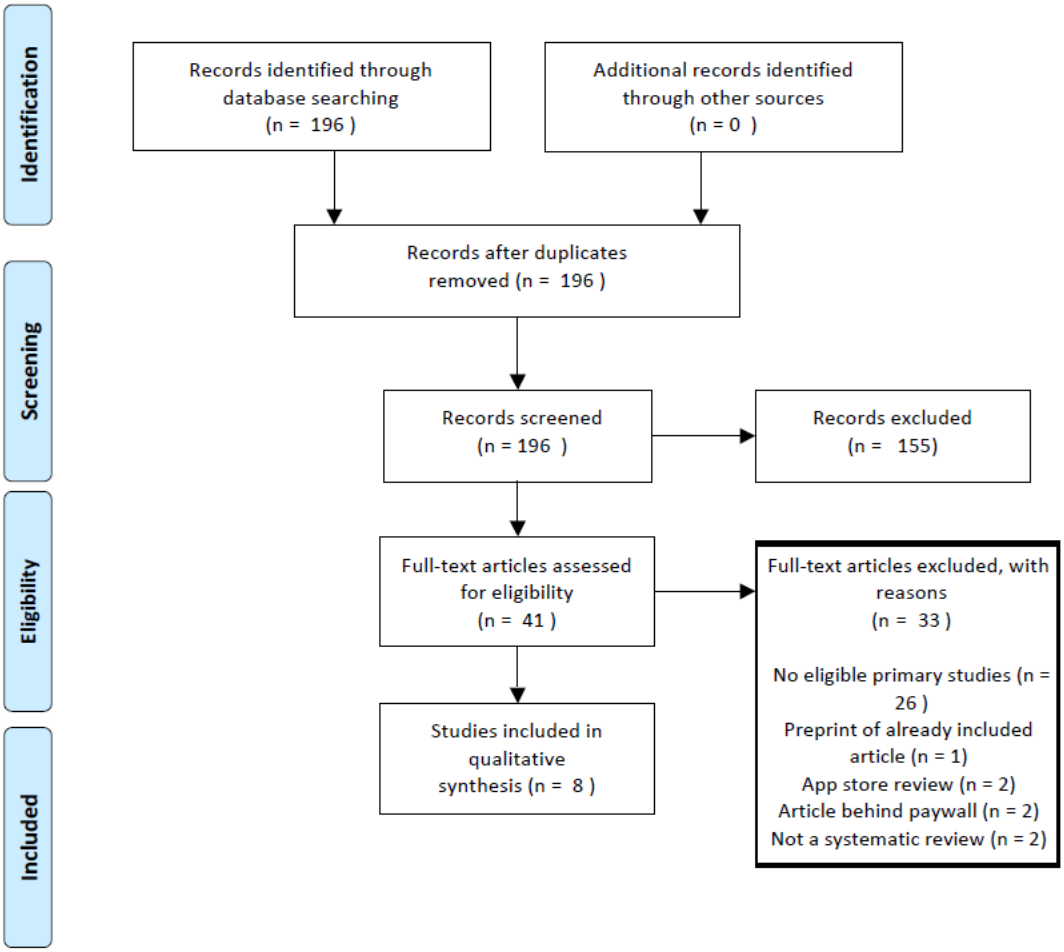
Then, one author (T.O.) selected eligible studies according to the following criteria:

- Inclusion criteria: Systematic reviews, including at least 1 primary study on COVID-19, including at least 1 primary study describing technology-based or non-technology-based reorganization of care.
- Exclusion criteria: Reviews of apps available on smartphone app stores (i.e., not including any studies), reviews including only primary studies on the diagnostic accuracy of technology-based interventions implemented during the COVID-19 pandemic.

After screening, we included the following 8 systematic reviews:

1. Boyce L, Nicolaides M, Hanrahan JG, Sideris M, Pafitanis G. The early response of plastic and reconstructive surgery services to the COVID-19 pandemic: A systematic review. Journal of Plastic, Reconstructive & Aesthetic Surgery. 2020.
2. Davalbhakta S, Advani S, Kumar S, Agarwal V, Bhoyar S, Fedirko E, Misra DP, Goel A, Gupta L, Agarwal V. A systematic review of smartphone applications available for corona virus disease 2019 (COVID19) and the assessment of their quality using the mobile application rating scale (MARS). Journal of medical systems. 2020 Sep;44(9):1-5.
3. Golinelli D, Boetto E, Carullo G, Nuzzolese AG, Landini MP, Fantini MP. Adoption of Digital Technologies in Health Care During the COVID-19 Pandemic: Systematic Review of Early Scientific Literature. Journal of medical Internet research. 2020;22(11):e22280.
4. Hojaij FC, Chinelatto LA, Boog GH, Kasmirski JA, Lopes JV, Sacramento FM. Surgical Practice in the Current COVID-19 Pandemic: A Rapid Systematic Review. Clinics. 2020;75.
5. Monaghesh E, Hajizadeh A. The role of telehealth during COVID-19 outbreak: A systematic review based on current evidence. BMC Public Health. 2020:20.
6. Prakash L, Dhar SA, Mushtaq M. COVID-19 in the operating room: a review of evolving safety protocols. Patient Safety in Surgery. 2020 Dec;14(1):1-8.
7. Tebeje TH, Klein J. Applications of e-Health to Support Person-Centered Health Care at the Time of COVID-19 Pandemic. Telemedicine and e-Health. 2020.
8. Yue JL, Yan W, Sun YK, Yuan K, Su SZ, Han Y, Ravindran AV, Kosten T, Everall I, Davey CG, Bullmore E. Mental health services for infectious disease outbreaks including COVID-19: a rapid systematic review. Psychological Medicine. 2020 Nov 5:1-6.

The PRISMA flow chart is presented below:



Qualitative data extraction was performed by one author (T.O.) by using content analysis. The author sought to identify components of technology or nontechnology based reorganization of care from primary studies included in the systematic review, by examining the results section and the summary tables of the 8 included reviews. The identified components of reorganization of care were synthesized in a single list by comparing the extracted data across systematic reviews and merging similar components into a single entry. A revised version of this list, written in non-technical language, was presented to the survey participants to illustrate the concept of blended care and to encourage idea generation.

eMethods 3: Description of survey development and piloting

Questions 1-2

Question development

The first two questions were developed based on brief solution-focused therapy counseling techniques. One technique used in solution-focused therapy is visualization of the future at a time when the patient's therapy goal will have been achieved. The counselor can ask questions to bring this ideal future into focus. For example, a patient who comes into therapy with the request to grow their self-confidence may be asked to describe a day in the future, when they will have become self-confident, in great detail (e.g., "How would your self-confidence show in work meetings?", "How will family dinners be different then compared to now?"

Based on this, the authors drafted the following questions:

"Imagine the ideal care for yourself, in the long term. In which ways would it be different from the regular care you received before the pandemic?

Which components of your pre-pandemic care would be carried over to your ideal care?

Which components of your pre-pandemic care would be removed completely or replaced by pandemic-care innovations, to achieve your ideal care?

How would the innovations in health care delivery, implemented during the pandemic and presented above help you obtain this ideal care?"

Question testing in cognitive interviews and piloting

We then conducted cognitive interviews with 3 patients (a 26-year-old woman with major depressive disorder, a 20-year-old woman with type 1 diabetes and generalized anxiety disorder, and a 57-year-old woman with hypothyroidism).

The patients were presented with a draft of the survey on the ComPaRe platform and were asked to complete it while thinking out loud, in the presence of one of the authors (T.O.). At the end of each webpage, the patients were asked standard cognitive interviewing questions (e.g., "What do you think this question is trying to identify?", "Could you rephrase this question, in your own words?"), and were asked to provide any suggestions that could improve the study.

Based on the feedback, we retained the first and last question reported above. Questions two and three produced no original data (i.e., they elicited responses that were repetitive of previous responses). We also decided to merge the two questions:

"Imagine the ideal care for yourself, in the long term. In which ways would it be different from the regular care you received before the pandemic? How would the innovations in health care delivery, implemented during the pandemic and presented above help you obtain this ideal care? "

Finally, the survey was pilot-tested with four participants of the ComPaRe cohort. Pilot-testing replicated the dissemination process of the final survey: the four participants received an email inviting them to participate in the survey, containing a link to their account on the ComPaRe platform, where the survey could be completed. They were additionally asked to time survey completion. After completing the main survey, participants were asked 3 additional questions in a separate webpage: the duration of survey completion, to describe any problems or difficulties they encountered in the survey and to propose additional modifications that, in their view, could improve the survey (open-ended questions).

Survey completion lasted an average of 21 minutes (range: 5-30 minutes). Participants main difficulty was caused by the term « ideal care », which was not specified further. Participants were unsure whether

the term referred to ideal care for themselves, physicians, the care system, patients in general, etc. The question was reworded to specify this. Participants also proposed that the question be broken into two smaller questions. This led to the final version of the question:

"Imagine the ideal care for yourself, in the long term. By ideal care we mean the care you wish to receive as a patient, according to your own criteria (e.g., more effective, less burdensome, etc.).

1. In which ways would it be different from the regular care you received before the pandemic?
2. How would the innovations in health care delivery, implemented during the pandemic and presented above help you obtain this ideal care?"

Questions 3-5

Question development

The following three compulsory questions refer to the use of alternative traditional care modalities. The authors aimed to develop questions that were not vague or general (e.g., "Would you use teleconsultations in the future?"). Inspired by the use of percentages and proportions, which is a common technique used to develop concrete goals in psychotherapy (e.g., "I will commute to work by bike instead of by car 3 days out of 5"), the authors developed the following question format:

"For what proportion of your future consultations, would you choose to use teleconsultations?"

Question testing in cognitive interviews and piloting

Patients provided positive feedback for this question in the cognitive interviews. They found it easy to conceptualize their care as a whole that can be completed partially by using new care modalities. Both the participants and interviewer found that the thinking process that led participants to select a proportion was informative, and should be captured for further analysis. Therefore, the participants and the interviewer agreed to add an optional open-ended question to each of the close-ended questions:

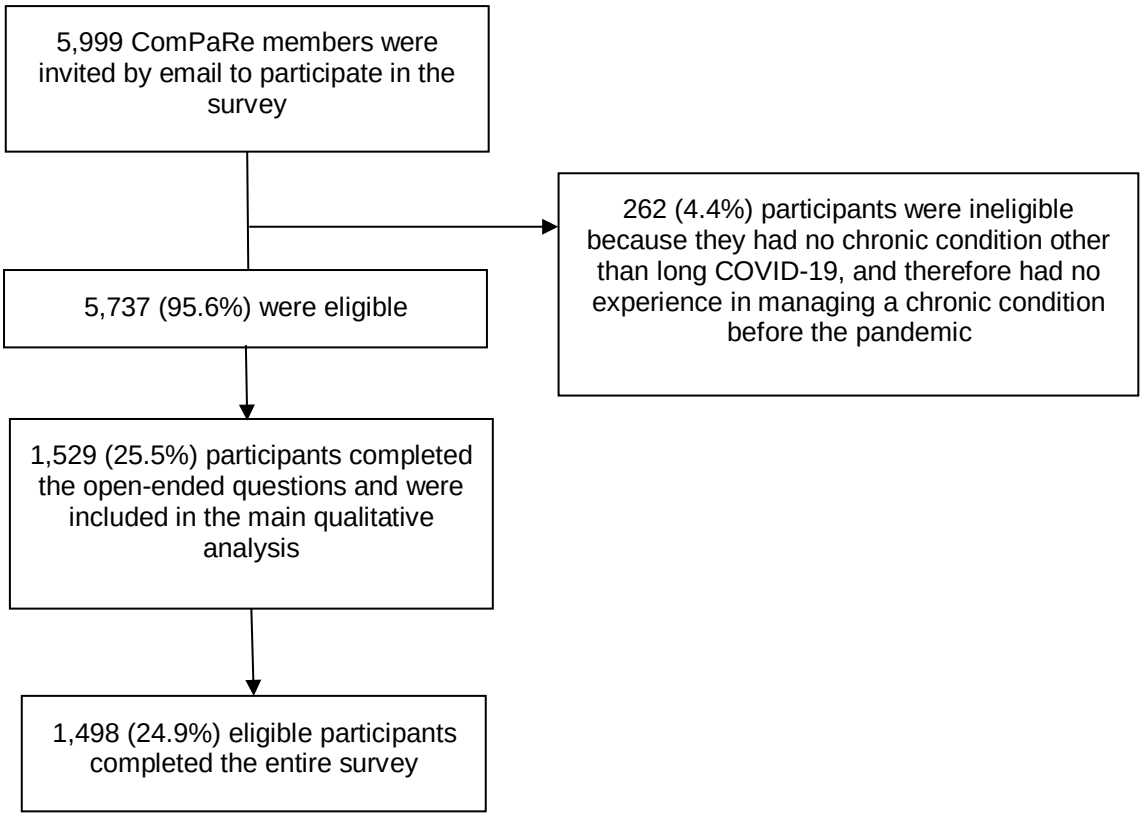
"Please use the text box below to explain why you chose this response."

Pilot-testing did not lead to any changes in questions 3-5.

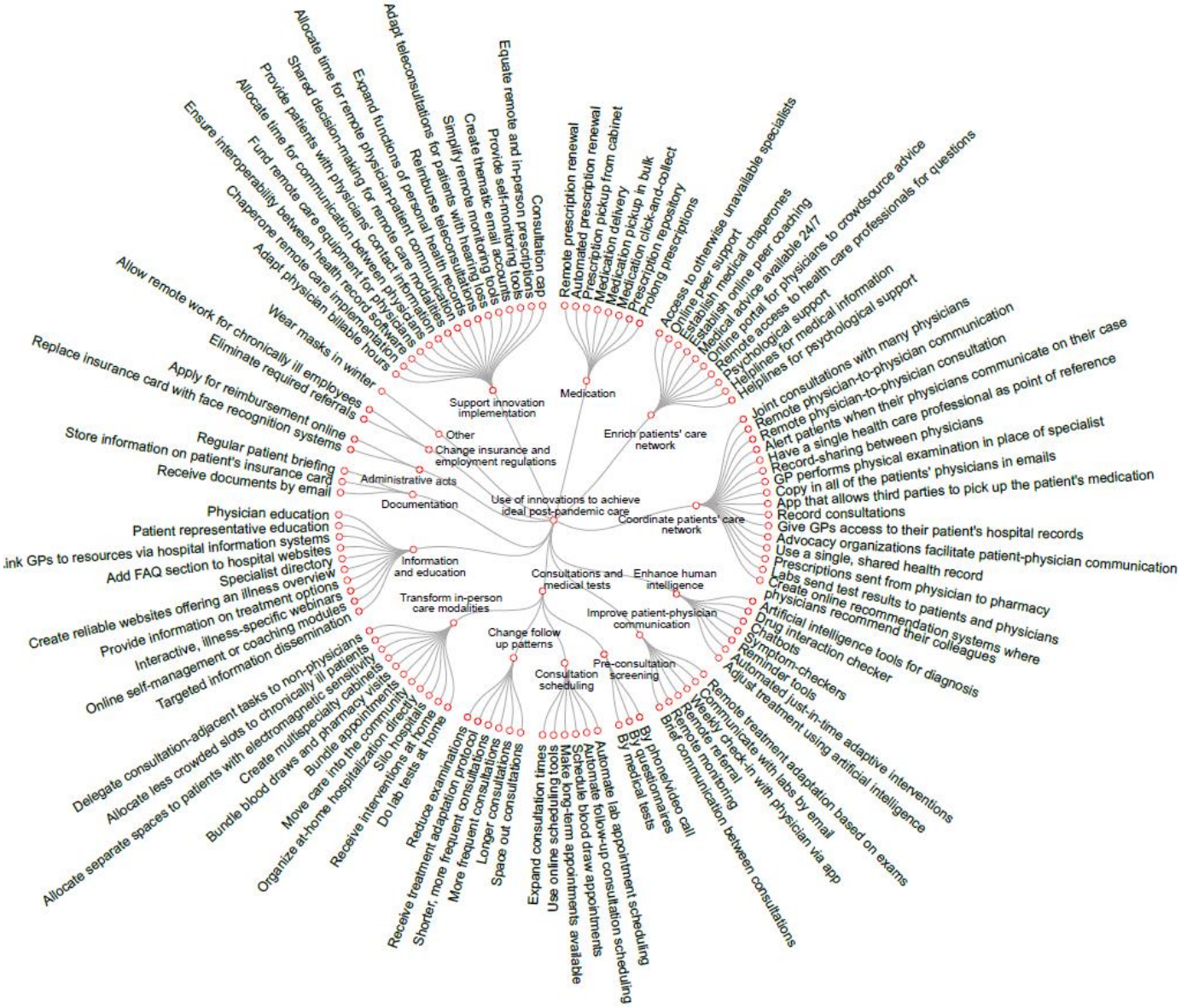
Cover letter

We drafted a brief cover letter that was sent to participants via e-mail, describing the purpose of the survey, the completion time (determined from piloting the survey with four participants, see below), and a link to the participant's account on the ComPaRe website where they could complete the survey. The cover letter was accompanied by the name and photograph of one of the authors (V.T.T.). The cover letter was presented to participants in cognitive interviewing and piloting. No modifications were proposed by participants.

eFigure 1 : Flow chart

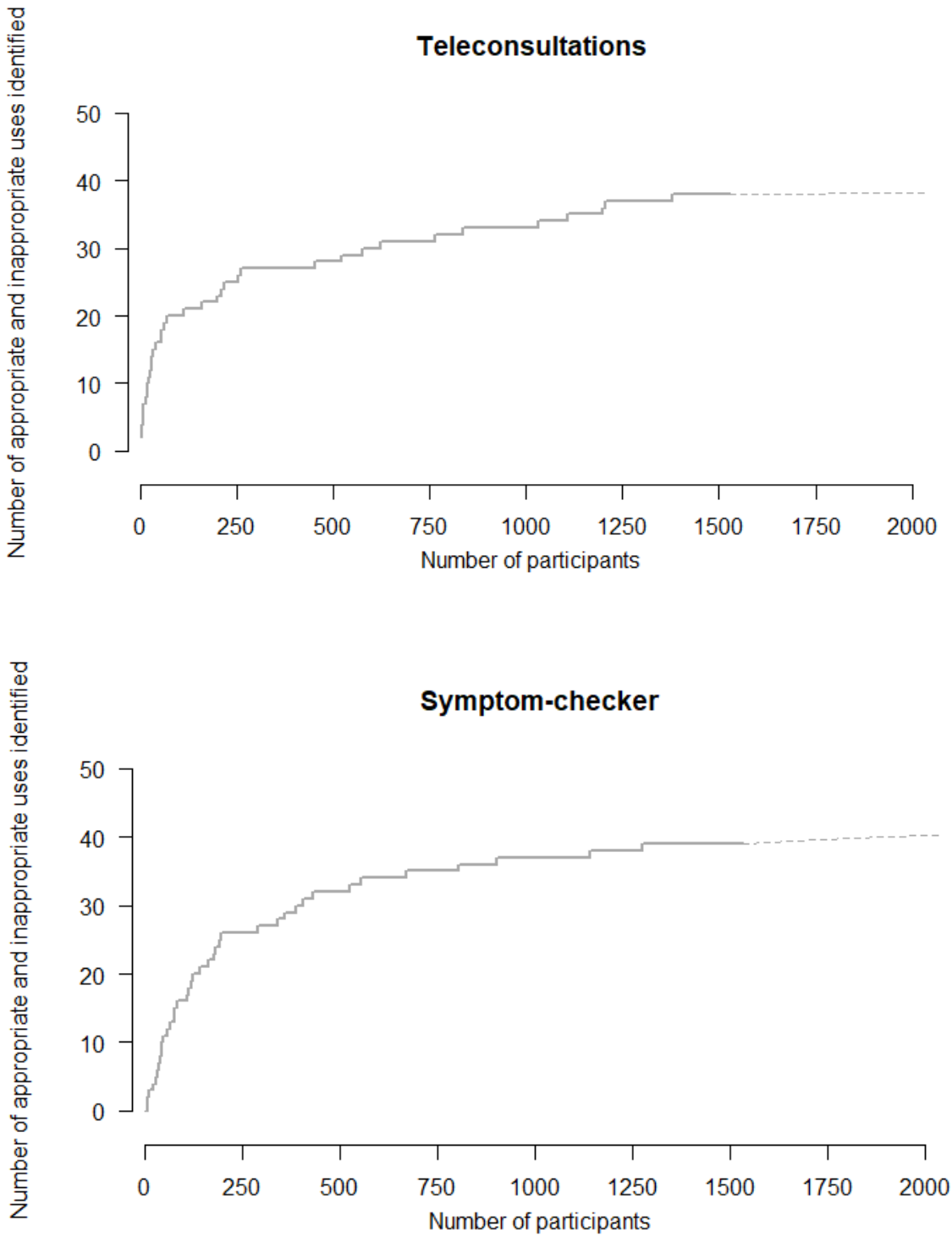


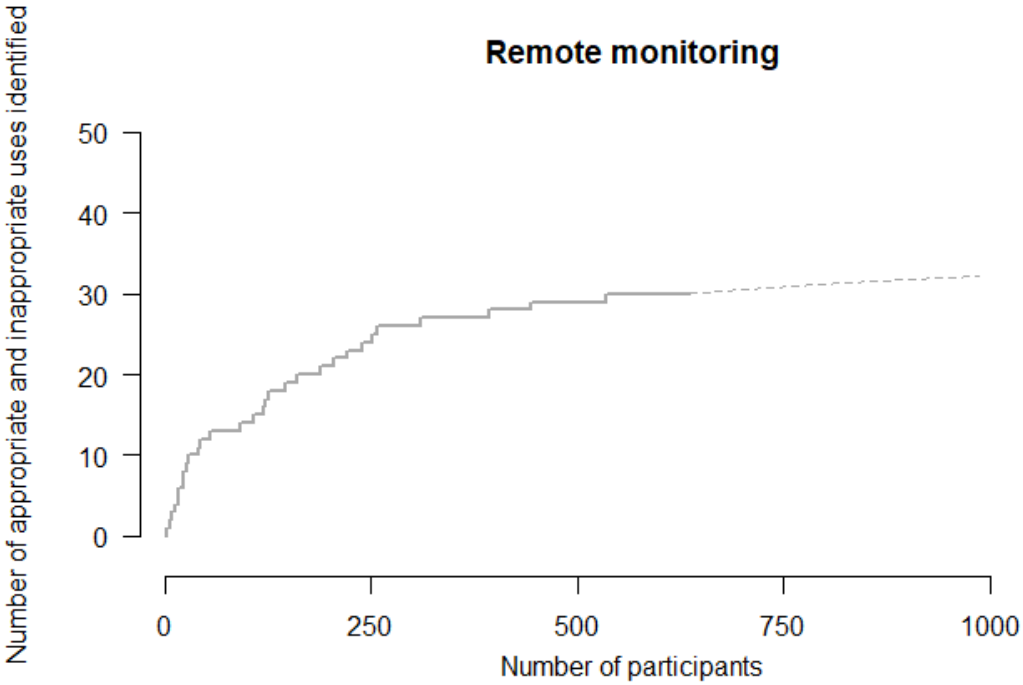
eFigure 2. Suggested uses of alternative care modalities implemented during the pandemic in post-pandemic care



The figure presents 114 suggestions to use alternative care modalities to achieve patients' ideal post-pandemic care, as suggested by 1,529 study participants. The suggestions are grouped into 11 categories: consultations and medical tests (n=33 actions), improve patient-physician communication (n=6), medication (n=8), enrich patients' care network (n=10), coordinate patients' care network (n=16), enhance human intelligence (n=7), support blended care implementation (n=16), information and education (n=10), documentation (n=3), administrative acts (n=2), change insurance and employment regulations (n=2).

eFigure 3: Cumulative code accumulation curve representing data saturation





The continuous line in each panel represents the codes (i.e., appropriate and inappropriate uses of each alternative care modality) identified in the responses provided by 1,529 participants in our study. The dotted line represents the potential number of codes that could have been identified by recruiting 500 additional participants. Note that the sample size for remote monitoring is 636 instead of 1,529, because only participants who use monitoring to manage their illness were eligible to answer the question on remote monitoring.

eTable 1: Characteristics of responders, non-responders, and ComPaRe cohort participants (unweighted sample).

Participant characteristics, N (%)	**Non-responders (n=4208)**	**Responders (n=1529)**	**ComPaRe cohort (n=24374)** [f]
Sex			
Men	608 (20.4)	457 (29.9)	4605 (18.9)
Missing data	NA	NA	359 (1.5)
Age (y), mean ± SD [a]	44.13 ±14.13	50.28 ±14.73	43.79 (13.99)
Education			
Lower education	123 (2.9)	44 (2.9)	691 (2.8)
Middle school or equivalent	436 (10.4)	148 (9.7)	2568 (10.5)
High school or equivalent	717 (17.0)	226 (14.8)	4012 (16.5)
Associate's degree	811 (19.3)	323 (21.1)	4715 (19.3)
Undergraduate or graduate degree	2121 (50.4)	788 (51.5)	11216 (46.0)
Missing data	NA	NA	856 (35.1)
Multimorbidity			
Yes	2222 (52.8)	1062 (69.5)	10201 (41.9)
Missing data	NA	NA	358 (1.5)
Years since first diagnosis, median [IQR] [b]	10.00 [4.00, 22.00]	16.00 [6.00, 28.00]	9.00 [4.00, 21.00]
Self-reported diagnosis [c]			
Endometriosis	1357 (32.2)	303 (19.8)	8643 (35.5)
Depression	350 (8.3)	149 (9.7)	1458 (6.0)
High blood pressure	349 (8.3)	266 (17.4)	1764 (7.2)
Diabetes	264 (6.3)	148 (9.7)	1291 (5.3)
Cancer	222 (5.3)	114 (7.5)	1013 (4.2)
Asthma	300 (7.1)	130 (8.5)	1397 (5.7)
Number of illnesses, median (interquartile range [IQR]) [d]	2.00 [1.00, 3.00]	2.00 [1.00, 4.00]	1.00 [1.00, 2.00]
Total score, Treatment Burden Questionnaire, median (IQR) [e]	53.00 [30.00, 79.00]	55.00 [29.00, 80.00]	NA

[a] Missing data for n=360 in the full ComPaRe cohort (last column).

[b] Missing data for n=359 in the full ComPaRe cohort (last column).

[c] Non-exhaustive list. List of the most frequently reported conditions. Some participants reported multiple conditions.

[d] Missing data for n=358 in the full ComPaRe cohort (last column).

[e] Missing data for n=1,358. This variable is not available for the entire ComPaRe cohort, because it is not part of the baseline questionnaire.

[f] Patients enrolled in the cohort that have provided informed consent and completed the baseline questionnaire. Data extracted on 27 January 2021.

eTable 2: Quantitative outcomes indicating the ideal use of alternative care modalities as a proportion of total relevant care needs, in the unweighted and weighted sample. [a]

Outcome	**Unweighted sample (n=1529)**	**Weighted sample (n=1529)**
Consultations		
Prefers primarily teleconsultations (alternative care modality)	476 (31.1)	477 (31.2)
Prefers primarily in-person consultations (traditional care modality)	752 (49.2)	719 (47.0)
Prefers entirely in-person consultations	277 (18.1)	312 (20.4)
No response	24 (1.6)	21 (1.3)
Ideal proportion of teleconsultations, median (interquartile range [IQR])	50.00 [20.00, 53.00]	50.00 [11.00, 52.00]
Reacting to new symptoms		
Prefers primarily to use symptom-checkers (alternative care modality)	314 (20.5)	357 (23.4)
Prefers primarily to contact their physician (traditional care modality)	702 (45.9)	574 (37.5)
Prefers entirely to contact their physician	482 (31.5)	564 (36.9)
No response	31 (2.0)	34 (2.2)
Ideal proportion of symptom-checker use, median [IQR]	22.50 [2.00, 50.00]	22.00 [2.00, 50.00]
Monitoring [a]	**n=636**	**n=669**
Prefers primarily remote monitoring and treatment adaptation (alternative care modality)	370 (58.1)	377 (56.4)
Prefers primarily to share monitoring data and adapt treatment during in-person consultations (traditional care modality)	197 (31.0)	192 (28.7)
Prefers entirely to share monitoring data and adapt treatment during in-personconsultations	69 (10.8)	100 (14.9)
No response	0 (0.0)	0 (0.0)
Ideal proportion of remote monitoring, median [IQR]	63.50 [40.00, 95.25]	52.30 [25.46, 85.41]

[a] Weighted data were obtained after calibration on margins for sex, age and educational level by using data from a national census describing the French population with chronic illness.
[b] Calculated only for participants who use monitoring to manage their illness. Participants who did not state they use monitoring were not eligible to answer this question.

eTable 3: Results of linear models in the weighted sample. [a,b]

	Ideal proportion of alternative care modality use								
	Teleconsultations (n=1299) [c]			Symptom-checker (n=1294)			Remote monitoring (n=544)		
Predictors	**Coefficient**	**95% CI**	**p**	**Coefficient**	**95% CI**	**p**	**Coefficient**	**95% CI**	**p**
(Intercept)	32.47	28.24 — 36.69	<0.001	32.83	28.72 — 36.94	<0.001	-3.26	-37.48 — 30.95	<0.001
Participant characteristics									
Education (reference category: lower education)									
Middle school or equivalent	-	-	-	-	-	-	32.04	12.81 — 51.26	0.001
High school or equivalent	-	-	-	-	-	-	32.03	13.79 — 50.27	<0.001
Associate's degree	-	-	-	-	-	-	31.46	12.91 — 50.01	<0.001
Undergraduate or graduate degree	-	-	-	-	-	-	31.04	12.74 — 49.34	<0.001
Feeling about household income (reference category: Finding it very difficult on present income)									
Living comfortably on present income	-	-	-	-	-	-	40.92	9.93 — 71.91	0.009
Endometriosis	-	-	-	-8.45	-14.62 — -2.27	0.007	16.19	7.16 — 25.23	<0.001
Cancer	-	-	-	-	-	-	-27.08	-43.38 — -10.78	0.001
Asthma	-	-	-	-12.35	-21.86 — -2.83	0.011	-	-	-
Prior teleconsultation use	18.02	11.79 — 24.25	<0.001	-	-	-	-	-	-

[a] Weighted data were obtained after calibration on margins for sex, age and educational level by using data from a national census describing the French population with chronic illness.
[b] The models are fit in the complete-case subset (n=1299 for teleconsultations, n=1294 for symptom-checker, n=544 for remote monitoring).
[c] Adjusted R^2 for teleconsultation model: 0.09, for symptom-checker model: 0.017, for remote monitoring model: 0.24.

eTable 4: Code list for the appropriate and inappropriate uses of alternative care modalities. Overarching category labels in bold.

Appropriate and inappropriate uses of alternative care modalities							
Code name	**Code definition**	**Unweighted, teleconsultations (n=1529), n (%)**	**Weighted, teleconsultations (n=1529), n (%)**	**Unweighted, symptom-checker (n=1529), n (%)**	**Weighted, symptom-checker (n=1529), n (%)**	**Unweighted, remote monitoring (n=1529), n (%)**	**Weighted, remote monitoring (n=1529), n (%)**
Care activities							
Adapt treatment -	Remote care is inappropriate to confirm the efficacy of a newly prescribed treatment and quick treatment/dosage changes until the right fit for the patient is found.	24 (1.6)	10 (0.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Adapt treatment +	Remote care is appropriate to confirm the efficacy of a newly prescribed treatment and quick treatment/dosage changes until the right fit for the patient is found.	3 (0.2)	7 (0.4)	0 (0.0)	0 (0.0)	20 (3.1)	39 (5.8)
Address minor complaints +	Remote care is appropriate for minor complaints as opposed to serious, severe symptoms.	14 (0.9)	13 (0.8)	29 (1.9)	12 (0.8)	1 (0.2)	1 (0.2)
Address specific questions +	Remote care is appropriate to answer specific (i.e., limited in scope) questions of the patient or the physician.	37 (2.4)	17 (1.1)	4 (0.3)	8 (0.5)	0 (0.0)	0 (0.0)
Annual/in-depth consultation -	Remote care is inappropriate for the patient's annual consultation, the consultation in which the patient and the physician do a more in-depth review the patient's overall health status.	20 (1.3)	11 (0.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
As a learning tool about the disease +	Remote care can be used to help patients understand their illness better.	0 (0.0)	0 (0.0)	1 (0.1)	6 (0.4)	1 (0.2)	1 (0.1)

As consultation aid +	The remote care tool can be used to collect information that can facilitate subsequent consultations with physicians (including to identify which physician they should contact, e.g., which of their specialists), or help patients better understand the diagnosis and instructions given to them by their physician after the consultation.	0 (0.0)	0 (0.0)	24 (1.6)	12 (0.8)	7 (1.1)	6 (0.8)
Communication on sensitive issues -	Remote care is inappropriate for discussing sensitive topics, including receiving worrisome news (e.g., a new diagnosis).	10 (0.7)	4 (0.3)	1 (0.1)	0 (0.0)	0 (0.0)	0 (0.0)
Discuss medical test results -	Remote care is inappropriate for discussing medical test results.	2 (0.1)	12 (0.8)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Discuss medical test results +	Remote care is appropriate for discussing medical test results.	40 (2.6)	21 (1.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
For informal caregivers +	The remote care tool can be used by the patient's informal caregivers to further support the patient.	0 (0.0)	0 (0.0)	2 (0.1)	2 (0.1)	0 (0.0)	0 (0.0)
For information purposes +	The remote care tool should be used for information purposes only, similar to a website publishing generic health information.	0 (0.0)	0 (0.0)	6 (0.4)	3 (0.2)	0 (0.0)	0 (0.0)
Identify symptom-disease link +	Remote care is appropriate to help patients identify if a new/worsening symptom is linked to their chronic disease or to a different disease.	0 (0.0)	0 (0.0)	9 (0.6)	7 (0.5)	1 (0.2)	0 (0.0)
Identify treatment misuse -	Remote care is inappropriate to identify the intentional or accidental misuse of potentially dangerous medication, such as opioids.	1 (0.1)	1 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Identify treatment misuse +	Remote care is appropriate to identify the intentional or accidental misuse of	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.3)	1 (0.1)

	potentially dangerous medication, such as opioids.						
Joint consultations +	Remote care is appropriate for patients who would like to have consultations with more than one physician simultaneously.	3 (0.2)	1 (0.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Physical examination -	Remote care is inappropriate for physical examination. This includes any examination that traditionally requires the patient's physical presence, such as taking blood pressures, neurological tests, blood draw, ultrasounds, etc. Use this code if the participant says that in-person care is preferrable because it offers opportunity for physical-examination, which is necessary in medical care, or because their illness requires physical examination. Note that the need for physical examination does not have to be objective (e.g., participants may phrase it as a preference for physical examination). Do not use this code if the participant refers to the need or preference for in-person social contact with their physician without specifically referring to examination.	486 (31.8)	365 (23.9)	0 (0.0)	0 (0.0)	7 (1.1)	17 (2.5)
Physical intervention -	Teleconsultations are inappropriate when physical interventions, such as intravenous drips, are required.	35 (2.3)	30 (1.9)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Pluridisciplinary day hospital -	Remote care is inappropriate to replace the care received by multiple experts during day hospitalizations.	1 (0.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Prescription renewal +	Remote care is appropriate for renewing prescriptions.	209 (13.7)	188 (12.3)	0 (0.0)	0 (0.0)	2 (0.3)	7 (1.1)

Replace online information-seeking +	Remote care can be used to replace information-seeking in non-legitimate/unvetted websites or forums, which may give the patient erroneous information.	0 (0.0)	0 (0.0)	6 (0.4)	1 (0.1)	0 (0.0)	0 (0.0)
Routine follow-up consultations -	Teleconsultations are inappropriate for routine consultations (e.g., follow-up to control a stable condition, consultations described as "just a discussion to touch base" or "simple follow-ups" by participants). Do not use this code if the participants state a specific reason (corresponding to another code) why teleconsultations are inappropriate for routine follow-up, such as the need for physical examination.	7 (0.5)	8 (0.5)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Routine follow-up consultations +	Teleconsultations are appropriate for routine consultations (e.g., follow-up to control a stable condition, consultations described as "just a discussion to touch base" or "simple follow-ups" by participants).	96 (6.3)	67 (4.4)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
To prepare in-person consultation +	Teleconsultations are appropriate to decide if an in-person consultation is needed.	4 (0.3)	6 (0.4)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
To rapidly appraise urgency +	Remote care is appropriate to appraise the urgency and severity one's symptoms and assess whether they should seek medical help. This helps patients feel reassured and avoid unnecessary consultations. Participants state that remote care can be used as a decision aid for the patient to estimate whether they should seek urgent care, schedule a consultation with their	1 (0.1)	0 (0.0)	98 (6.4)	75 (4.9)	7 (1.1)	9 (1.3)

	physician soon, or wait until the next scheduled consultation.						
To supplement physician's abilities +	Remote care is appropriate when the patient's physician requires support (e.g., younger, less experienced physicians; physicians who have followed the patient for a long time and may become less attentive over time).	0 (0.0)	0 (0.0)	5 (0.3)	5 (0.4)	0 (0.0)	0 (0.0)
Urgent needs -	Remote care is inappropriate to address urgent needs in which medical advice is rapidly required.	1 (0.1)	0 (0.0)	12 (0.8)	27.3 (1.8)	0 (0.0)	0 (0.0)
Urgent needs +	Remote care is appropriate to address urgent needs in which medical advice is rapidly required. This may refer to participants' view that teleconsultation appointments are easier to obtain with shorter delays than in-person consultations, so that they can rapidly address emerging needs for medical care.	62 (4.2)	57 (3.7)	7 (0.5)	10 (0.6)	4 (0.6)	1 (0.2)
Use with General Practitioners (GPs) -	The remote care tool should not be used with one's general practitioner (as opposed to one's specialist).	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.2)	0 (0.0)
Validate patient's self-diagnosis +	Remote care is appropriate for supporting patients' own expertise (e.g., after a patient examines their symptoms and decides on the best course of action, a symptom-checker can be used to confirm the patient's decision).	0 (0.0)	0 (0.0)	6 (0.4)	3 (0.2)	0 (0.0)	0 (0.0)
When other types of care are unavailable +	Using a symptom-checker is appropriate when traditional care is unavailable (e.g., on the weekend or at night, when the patient's physician cannot be reached, when the patient's physician may be unwilling to provide a phone consultation, when the next available	0 (0.0)	0 (0.0)	30 (2.0)	35 (2.3)	1 (0.2)	0 (0.0)

	consultation is too far from the appearance of a symptom).						
Care innovation characteristics							
If data safety is guaranteed +	Data safety/online safety guarantees are a requisite (as a characteristic of the remote care tool) for appropriate remote care use	3 (0.2)	2 (0.1)	8 (0.5)	2 (0.1)	16 (2.5)	12 (1.9)
If it is used at the correct frequency +	Correct frequency of use is a requisite (as a characteristic of the remote care tool) for appropriate remote care use.	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.3)	1 (0.1)
If it takes multimorbidity into account +	Remote care should be used if the tools take multimorbidity into account.	0 (0.0)	0 (0.0)	2 (0.1)	0 (0.0)	0 (0.0)	0 (0.0)
If payment/reimbursement is improved	Facilitation of the payment and reimbursement process is a requirement for the use of remote care.	2 (0.1)	7 (0.4)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
If the algorithm is personalized +	A necessary condition to use symptom-checkers is that the patient's own data are included to complement the generic diagnostic algorithm.	0 (0.0)	0 (0.0)	8 (0.5)	3 (0.2)	0 (0.0)	0 (0.0)
If the measure is detailed enough +	Remote care should be used if the tools collect adequately detailed information.	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.3)	0 (0.1)
If the patient has control over sending the data +	Remote care should be used if the patient has control over when their data will be sent to or accessed by their physician.	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	4 (0.6)	2 (0.2)
If the tool is explained by the physician +	A necessary condition to use symptom-checkers is that the physician explains their use to the patient in advance.	0 (0.0)	0 (0.0)	2 (0.1)	1 (0.1)	2 (0.3)	1 (0.1)
If the tool is supervised by a physician +	Use of remote care tools (symptom-checkers and remote monitoring) requires that they are supervised by a physician in one of the following ways: 1) in case of alert, the results of the symptom-checker are directly sent to a physician who takes over the process, or 2) when the	0 (0.0)	0 (0.0)	13 (0.9)	4 (0.3)	23 (3.6)	27 (4.1)

	symptom-checker has produced a result, a physician calls the user to review/go in-depth in the diagnostic (regardless of alert), 3) using remote monitoring requires the certainty that the monitored data will be reviewed and taken into account by the physician.						
If the tools are provided to patients +	Being provided with the monitoring tools is necessary for the patient to take up remote monitoring.	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	4 (0.6)	2 (0.3)
If there is quality assurance +	Quality assurance or vetting (such as an official recommendation of a symptom-checker website from the French national health system) is a requisite (as a characteristic of the remote care tool) for appropriate remote care use, to separate legitimate from lesser-quality versions of the remote care tool. Participants state they would need help to judge if a tool is trustworthy in order to use it.	0 (0.0)	0 (0.0)	27 (1.8)	12 (0.8)	2 (0.3)	1 (0.1)
Patient characteristics							
Emerging illnesses -	Remote care is appropriate for illnesses known in the medical community. It is inappropriate for new, emerging illnesses for which a solid knowledge base does not exist.	1 (0.1)	0 (0.0)	2 (0.1)	1 (0.0)	0 (0.0)	0 (0.0)
Employed patients +	Remote care is appropriate for employed patients who may find it difficult or undesirable to take time off work for in-person care.	19 (1.2)	12 (0.8)	1 (0.1)	0 (0.0)	0 (0.0)	0 (0.0)
Established patient-physician relationship +	Remote care should be used only after a supportive and trusting patient-physician relationship has been established.	10 (0.7)	8 (0.5)	0 (0.0)	0 (0.0)	5 (0.8)	1 (0.2)

Heterogeneous, multifactorial or atypical symptoms -	Remote care is inappropriate for patients whose symptoms are atypical for their condition, or symptoms that vary in their manifestation from day to day, and are affected by multiple factors (e.g., stress, nutrition, etc.)	0 (0.0)	0 (0.0)	19 (1.2)	8 (0.5)	1 (0.2)	0 (0.0)
Infrequent consultations -	Remote care is inappropriate for patients who already rarely consult their physician in person. This refers to the participant's subjective appraisal of consultations as infrequent, regardless of the actual frequency.	24 (1.6)	11 (0.7)	1 (0.1)	0.3 (0.0)	0 (0.0)	0 (0.0)
Infrequent consultations +	Remote car is appropriate for patients who rarely consult their physician in person. This refers to the participant's subjective appraisal of consultations as infrequent, regardless of the actual frequency.	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	6 (0.9)	4 (0.6)
Initial consultations -	Remote care is inappropriate for initial consultations establishing a new diagnosis and for newly diagnosed patients.	10 (0.7)	6 (0.4)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Initial consultations +	Remote care is appropriate for initial consultations establishing a new diagnosis and for newly diagnosed patients.	0 (0.0)	0 (0.0)	3 (0.2)	1 (0.1)	0 (0.0)	0 (0.0)
Lack of private personal space -	Teleconsultations are inappropriate for patients who do not have a private space at home where they can speak to their physician uninterrupted and in confidentiality (e.g., because they live with family).	6 (0.4)	4 (0.2)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Limited treatment variation -	Remote care is inappropriate for patients whose treatment protocol is rarely modified/cannot be modified irrespective	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	4 (0.6)	2 (0.3)

	of their symptoms, as opposed to patients whose treatment depends on their symptoms or vitals.						
Areas with few available physicians +	Remote care is appropriate for patients living in the countryside/locations with few available physicians in geographic proximity or far from reference centers specializing in the patient's illness.	48 (3.1)	51 (3.3)	3 (0.2)	19 (1.2)	0 (0.0)	0 (0.0)
Multimorbid patients -	Remote care is inappropriate for patients with multimorbidity (e.g., because of the burdensome nature of their care).	0 (0.0)	0 (0.0)	3 (0.2)	0 (0.0)	0 (0.0)	0 (0.0)
Multimorbid patients +	Remote care is appropriate for patients with multimorbidity (e.g., because of the burdensome nature of their care).	2 (0.1)	1 (0.0)	1 (0.1)	0 (0.0)	0 (0.0)	0 (0.0)
Patient expertise -	Remote care is inappropriate for patients who have in-depth knowledge and experience managing their illness, because it has little to contribute.	0 (0.0)	0 (0.0)	27 (1.8)	11 (0.7)	5 (0.8)	2 (0.2)
Patient expertise +	Remote care is appropriate for patients who have in-depth knowledge and experience managing their illness. Knowledge and experience are prerequisites that enable patients to use the tool efficiently and correctly.	4 (0.3)	9.1 (0.6)	10 (0.7)	3 (0.2)	5 (0.8)	4 (0.5)
Patient self-monitors +	For remote monitoring: it is appropriate for patients who already have a habit of self-monitoring. For teleconsultations: they are appropriate for patients who can self-monitor to enrich teleconsultations by providing monitoring data (e.g., blood pressure readings) to skip physical examinations.	10 (0.7)	11 (0.7)	0 (0.0)	0 (0.0)	4 (0.6)	2 (0.2)
Patients prone to anxiety regarding their health -	Symptom-checkers are inappropriate for patients who are likely to experience anxiety about their health. Use of the tool	0 (0.0)	0 (0.0)	45 (2.9)	35 (2.3)	0 (0.0)	0 (0.0)

	may lead these patients to overestimate the gravity of their symptoms or encourage rumination on their symptoms.						
Patients requiring closer follow-up than that offered by traditional care +	Remote care is appropriate for patients who require or prefer closer follow-up than that offered by traditional care in which consultations are infrequent, so that their treatment can be adapted quickly after a change in the patient's condition.	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	36 (5.7)	59 (8.8)
Patients who are temporarily away from home +	Remote care is appropriate for when patients are temporarily away from home on vacation or business, so that their care is not interrupted by their absence.	8 (0.5)	15 (1.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Patients with limited remote communication capacity -	Remote care is inappropriate for patients who have trouble with remote communications due to their illness (e.g., telephone phobia).	4 (0.3)	1 (0.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Patients with restricted mobility +	Remote care is appropriate for patients with reduced mobility due to physical or mental illness. Includes patients who experience physical pain when seated at waiting rooms for a long time.	32 (2.1)	37 (2.4)	1 (0.1)	0 (0.0)	0 (0.0)	0 (0.0)
Stable illness -	Remote care is inappropriate for patients with controlled, stable illness (i.e., in the absence of new symptoms or other evolution of the illness).	0 (0.0)	0 (0.0)	4 (0.3)	2 (0.1)	9 (1.4)	8 (1.1)
Stable illness +	Remote care is appropriate for patients with controlled, stable illness (i.e., in the absence of new symptoms or other evolution of the illness.	124 (8.1)	126 (8.3)	5 (0.3)	7 (0.4)	7 (1.1)	3 (0.5)
Symptoms can be observed and reported +	A necessary condition to use symptom-checkers is that the symptoms can be observed and reported accurately by patients with no need for special training.	0 (0.0)	0 (0.0)	43 (2.8)	28 (1.8)	4 (0.6)	2 (0.3)

	This depends on the illness (e.g., certain illnesses may be asymptomatic, or the symptoms may be difficult to accurately observe without help from a physician, such as psychiatric or dermatologic illnesses).						
To keep physician after moving +	Remote care is appropriate for patients who wish to maintain their physician after moving to a new location.	1 (0.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)

[a] Weighted data were obtained after calibration on margins for sex, age and educational level by using data from a national census describing the French population with chronic illness.

eTable 5: Code list for the attributes of ideal care and suggested uses of alternative care modalities to achieve ideal care. Overarching category labels in bold.

Attributes of ideal care			
Code name	**Code definition**	**Unweighted (n=1529), n (%)**	**Weighted (n=1529), n (%)**
Responsive	Care will be more dynamic and responsive to patients' needs. Patients will receive care (e.g., consultations with a specialist, treatment adaptation) exactly when care is needed, without having to wait several months for a consultation. Consultations will be responsive to patients' needs instead of following a non-personalized template that mandates follow-up appointments at pre-specified time intervals.	270 (17.7)	206 (13.5)
Empathetic	Care will be characterized by empathetic communication between patients and physicians. Physicians will have good communication skills and patients will feel heard, seen and understood.	77 (5.0)	63 (4.1)
Interconnected	The professionals involved in the patient's care network will communicate with each other to facilitate information exchange. The patient will not have to be the sole messenger transferring information on their illness(es) between professionals.	139 (9.1)	90 (5.9)
Collective	Care is described as a system in which resources are shared (e.g., less severely ill patients will receive remote care to free physicians' time for more severely ill patients).	10 (0.7)	3 (0.2)
Safe from infectious diseases	Refers to care being safe from infectious diseases (e.g., annual flu).	31 (2.0)	45 (2.9)
Holistic	Care will be holistic, treating the patient as a person instead of treating individual organs. This includes offering psychological support to patients.	58 (3.8)	29 (1.9)
Less burdensome to informal caregivers	Care will be less burdensome to patients' informal caregivers (i.e., family and friends who help the patient with their care).	6 (0.4)	4 (0.3)
Autonomy-supportive	Care will give patients more autonomy in the management of their health.	23 (1.5)	12 (0.8)
Single-tier	Blended care will not be a two-tier system, i.e., of higher quality for patients who can use remote technologies, and of lesser quality for patients who cannot.	22 (1.4)	31 (2.0)
Physician availability	Refers to the need for a greater number of physicians in general, or of physicians that are competent at managing the patient's illness. This code was not used for quotes that refer specifically to the time it takes to get a consultation with a specialist (the code Reactive was used instead).	62 (4.1)	43 (2.8)
Minimally disruptive	Care will disrupt patients' personal lives less (e.g., having to take time off work to attend in-person consultations).	52 (3.4)	20 (1.3)
More affordable	Out-of-pocket costs associated with care will be reduced.	46 (3.0)	36 (2.4)
Lean	There will be fewer in-person consultations considered unnecessary by the patient, thereby reducing associated travel and wait, the term "less heavy" was also coded as "Lean".	470 (30.7)	432 (28.2)

More personalised	Care will be personalised to each individual patient.	27 (1.8)	16 (1.0)
Informative	Information about the patients' illness and care will be clearly provided during their care, from official sources, such as by their physician, including orientation towards the right specialist for their illness. Patients will not have to struggle to get information about their illness or resort to unverified online resources. This refers to information about the illness and treatments, not one's personal data (e.g., adding exam results to a patient's health records).	45 (2.9)	34 (2.2)
Not redundant	Care will not require patients to do the same thing multiple times (e.g., to do the same blood test twice, because it was ordered by two different specialists a few weeks apart).	16 (1.0)	10 (0.7)
Automated	Some processes of care should be automated, instead of requiring vigilance and action from patients (e.g., taking follow-up appointments, having prescriptions automatically renewed without having to put in a request).	17 (1.1)	10 (0.7)
Closer follow-up	Patients will be followed more closely and regularly, by having more consultations, by having more frequent contact with their physician in-between consultations, or by using remote monitoring.	64 (4.2)	60 (3.9)
Better documented	The patient's care will be better documented. For example, all documents regarding the patient's illness, such as lab test results, will be available to patients and stored in their medical record, patients will regularly receive reports providing an overview of their illness and consultation 'minutes'. This is associated with reducing redundancy and improving information flows within the patient's care network (see codes "Not redundant" and "Interconnected"). This code does not refer to generic information about the patient's illness, but to their documentation of data produced by their personal care.	35 (2.3)	21 (1.4)
Maintain in-person patient-physician contact	Care will be at least partially based on in-person patient-physician encounters. It will not be fully remote, either for practical reasons (e.g., need for physical examination) or for social reasons (e.g., to maintain human contact and facilitate the patient-physician relationship) or due to patient preferences and beliefs regarding the superiority of in-person care.	233 (15.2)	199 (13.0)
As before	Care should return to traditional, pre-pandemic care. No remote care modalities used during the pandemic should be adopted in the long term, either because the patient's pre-pandemic care is ideal, or because they do not believe that their care can change drastically (e.g., because they consider pre pandemic levels of in-person care to be necessary).	131 (8.6)	143 (9.4)
Linked to research	Data collected in real-life settings, such as by self-monitoring, will be used in research to advance knowledge on the patient's illness.	1 (0.1)	0 (0.0)
Suggested use of alternative care modalities to achieve ideal care			
Code name	**Code definition**	**Prevalence in unweighted dataset, n (%)**	**Prevalence in weighted dataset, n (%)**

Consultations and medical tests	**Modifications to the scheduling or implementation of consultations or medical tests.**		
Consultation scheduling			
Automate lab appointment scheduling	When patients are prescribed lab tests or other examinations (e.g., ultrasound), there should be an automated process of taking an appointment for the tests.	1 (0.1)	0 (0.0)
Automate follow-up consultation scheduling	Pre-schedule the follow-up consultation (when needed) during the current consultation.	9 (0.6)	8 (0.5)
Schedule blood draw appointments	Patients will be able to book blood draw appointments with labs to avoid wait.	1 (0.1)	0 (0.0)
Make long-term appointments available	Patients will be able to make appointments further into the future.	1 (0.1)	0 (0.0)
Use online scheduling tools	Consultations (including hospital consultations) will be scheduled online via a dedicated website. The consultation scheduling website will offer functions such as presenting all available time slots so that the patient can choose the most convenient time slot, alerts when earlier consultation slots become available due to cancellation, and the option to select the reason for consultation (e.g., renew prescription, adapt treatment due to side effects), offering different time slots depending on urgency.	77 (5.0)	54 (3.5)
Expand consultation times	Expand the time slots available for patients to consult their physicians.	2 (0.1)	0 (0.0)
Pre-consultation screening			
Pre-consultation screening (phone/video call)	Patients have a brief phone or video call with their physician to decide if they need a consultation.	5 (0.3)	2 (0.2)
Pre-consultation screening (questionnaires)	Have a screening system to decide if the patient needs a consultation based on responses to regularly completed questionnaires on their symptoms.	3 (0.2)	1 (0.0)
Pre-consultation screening (medical tests)	Have a screening system to decide if the patient needs a consultation based on lab test results.	6 (0.4)	2 (0.1)
Change follow-up patterns			
Space out consultations	Prolong the time between consultations.	26 (1.7)	15 (1.0)
Longer consultations	Give patients more time with their physician per consultation	10 (0.7)	5 (0.3)
More frequent consultations	Patients will be able to consult their physician more frequently, in part thanks to remote care modalities.	19 (1.2)	16 (1.1)

Shorter, more frequent consultations	Care should comprise shorter but more frequent consultations.	5 (0.3)	1 (0.1)
Receive treatment adaptation protocol	Patients receive a protocol guiding them to test different treatments (e.g., different doses of the prescribed medication) until they find the one they respond best to.	1 (0.1)	0 (0.0)
Reduce examinations	Reduce the number of medical examinations and tests requested of patients.	1 (0.1)	1 (0.0)
Transform in-person care modalities			
Do lab tests at home	Biological samples required for lab tests, such as blood draws, will be taken at home by a health care professional or by the patient and then sent to a lab for analysis.	10 (0.7)	4 (0.3)
Receive interventions at home	Deliver interventions that are usually done in hospital, such as IV drips, at home instead.	11 (0.7)	14(0.9)
Silo hospitals	Establish separate hospitals for different patient groups according to their illness.	1 (0.1)	1 (0.0)
Organize at-home hospitalization directly	The patient can benefit from at-home hospitalization without having to pass by the emergency room first.	1 (0.1)	0 (0.0)
Move care into the community	Patients will be able to do medical acts, such as lab tests and medical visits, in their local community, instead of having to go to the hospital. For example, specialist physicians could practice at community health centres on prespecified dates, instead of patients having to travel to medical centres specialized in their illness located in a different region.	9 (0.6)	11 (0.7)
Bundle appointments	Bundle different appointments (exams, consultations) at the same place, on the same day	17 (1.1)	16 (1.0)
Bundle blood draws and pharmacy visits	Offer the option to do blood draws at the pharmacy and directly pick up the adapted medication based on the results.	1 (0.1)	1 (0.1)
Create multispecialty offices	Create medical offices that group physicians of all specialties relevant to a specific illness, including medical laboratory services, as a "one stop shop" for patients with a given illness.	5 (0.3)	2 (0.1)
Allocate separate spaces to patients with electromagnetic or multiple chemical sensitivity	Provide adapted care spaces for patients with Multiple chemical sensitivity and Electromagnetic hypersensitivity.	1 (0.1)	0 (0.0)
Allocate less crowded slots to chronically ill patients	Allocate less crowded time slots to chronically ill patients for in-person consultations, so they come in contact with fewer people (e.g., to minimize the risk of contracting an infectious disease)	1 (0.1)	0 (0.0)
Delegate consultation-adjacent tasks to non-physicians	Some consultation-adjacent tasks could be done by trained nurses or pharmacists. These may include routine consultations (in which the main aim is to check that the patient's condition remains stable by means of physical examination or review of test results, and renew their prescription), consultations aiming at prevention, or	8 (0.5)	11 (0.7)

	consultations with specialized nurses who, either alone or by consulting with a specialized physician, can support the patient and their family physician in managing the illness. Physicians could also collaborate with nurses in delivering blended care (e.g., local nurses could perform a physical examination and take the patient's vitals and transmit the data to the patient's physician, who then can adapt the patient's medication if needed).		
Introduce remote care modalities			
Use teleconsultations	Participants suggested that teleconsultations should be part of post-pandemic care. Participants differ regarding the way in which they suggest teleconsultations be used. Some participants emphasized that the choice of teleconsultations versus in-person consultations should be left up to the patient, and others highlighted the need to keep some in-person consultations. Some participants suggested that teleconsultations be used under specific conditions (e.g., when the illness is stable and no physical exam is required). Finally, some participants reported that teleconsultations would result in more regular or frequent care, and that teleconsultation appointments are easier to get with shorter delays, compared to in-person consultations.	658 (43.0)	594 (38.9)
Online physiotherapy	Replace physiotherapy consultations with pre-recorded or live online physiotherapy sessions.	2 (0.1)	0 (0.0)
Consultation-preparatory questionnaires	Before each consultation, patients can fill in questionnaires to provide physicians with information about their health.	1 (0.1)	0 (0.0)
Remote prescription for lab tests before consultation	Patients will be able to remotely receive prescriptions for lab tests (e.g., via email or through the patient portal associated with their personal health record). This will save patients a consultation whose sole purpose is the prescription of lab tests, and it can help patients do lab tests rapidly in response to the evolution of their illness (e.g., as soon as their symptoms worsen).	21 (1.4)	14 (0.9)
Text-based consultations	Patients will have the option of doing consultations in writing (by email, chat or text messaging), without verbal communication via video or phone calls, potentially supplemented by data (e.g., photographs of affected areas).	3 (0.2)	1 (0.1)
Joint consultations with many patients	Organize consultations where many patients can simultaneously consult with the same physician, on rather general, non-confidential topics.	2 (0.1)	1 (0.1)
Test patient-physician fit using teleconsultation	When patients seek a new physician, they can have a first teleconsultation to decide if they would like to pursue a therapeutic relationship with this physician.	3 (0.2)	1 (0.1)
Improve patient-physician communication	**Make communication between the patient and their regular physician(s) more responsive to the patient's needs outside of consultations.**		
Remote treatment adaptation based on exams	The patient's lab test results are sent to their physician, who then remotely adapts the patient's treatment, or simply renews their prescription remotely, without consultation. Additional	5 (0.3)	7 (0.5)

	information can be provided, such as the results of physical exams performed by non-physician health care professionals.		
Communicate with labs by email	Patients will be able to communicate with biomedical labs by email.	1 (0.1)	0 (0.0)
Weekly check-in with physician via app	Patients will be able to communicate with their regular physicians once a week via a dedicated app.	1 (0.1)	0 (0.0)
Remote referral	Obtain referral letter to a specialist physician remotely.	2 (0.1)	1 (0.1)
Brief communication between consultations	Being able to contact one's regular physician briefly, to address specific concerns or questions (e.g., about side effects of prescribed medication) in a synchronous or asynchronous manner. This may take the form of "mini teleconsultations" (i.e., brief 5- or 10-minute contact by phone or video call to address specific topics between proper consultations), e-mails, or chat via messaging platforms.	222 (14.5)	135 (8.8)
Remote monitoring	Transmission of monitoring data from a monitoring tool, such as a wearable sensor, a medical device, or a symptom log, to one's physician, for reactive treatment adaptation	92 (6.0)	66 (4.3)
Medication	**Facilitate patients' access to medication.**		
Remote prescription renewal	Patients will be able to obtain a prescription remotely, such as by email, after teleconsultations. This includes prescriptions for medication and lab tests.	322 (21.1)	283 (18.5)
Automated prescription renewal	The patient will have their medication prescription renewed remotely, without having a consultation or teleconsultation. The renewal may be automated for the same prescription, if the patient does not notify the physician of change in their condition, or it may be coupled with remote monitoring (i.e., the physician can renew or send a modified prescription, depending on the patient's monitoring data).	52 (3.4)	43 (2.8)
Prescription pickup from medical offices	The patient's prescription is renewed by the physician and the patient picks it up at their medical office/from their secretary without having to wait.	2 (0.1)	0 (0.0)
Medication delivery	Medication will be delivered to the patient's home. For patients who pick up their medication from the hospital pharmacy, medication may be delivered to their local pharmacy for pickup.	79 (5.2)	60 (3.9)
Medication pickup in bulk	Being able to pick up medication for more than 1 month at each pharmacy visit.	16 (1.0)	16 (1.0)
Medication click-and-collect	Patients can pre-order their medication and pick it up at their local pharmacy. This saves patients having to wait for their order to be put together at the pharmacy and spares them unnecessary trips to their pharmacy when their medication is out of stock.	9 (0.6)	5 (0.3)
Prescription repository	Online repository where physicians upload prescriptions for patients to download (possibly in a format that can be easily shared with their pharmacist, such as a QR code).	3 (0.2)	2 (0.2)
Prolong prescriptions	Prolong prescription validity	19 (1.2)	10 (0.6)
Enrich patients' care network	**Multiply the nodes in the patient's care network.**		
Access to otherwise	Patients can use communication technologies to remotely consult a specialist in their illness other than their regular physician. Technologies enable patients to reach experts that would	13 (0.9)	12.6 (0.8)

unavailable specialists	otherwise be inaccessible because of distance, or to reach many experts to efficiently obtain several opinions.		
Online peer support	Online support groups by peers with the same illness.	8 (0.5)	3.1 (0.2)
Establish "medical chaperones"	Create 'medical chaperones': non-physician professionals charged with supporting the care of patients, where physician skills are not required (e.g., informing patients about annual vaccination campaigns, teaching patients healthy cooking skills via online classes).	1 (0.1)	0.8 (0.1)
Establish online peer coaching	Establish an online platform where trained peers with the same illness as the patient provide support, supervised by a physician.	1 (0.1)	0 (0.0)
Medical advice available 24/7	Patients will be able to receive medical advice around the clock.	7 (0.5)	11.4 (0.7)
Online portal for physicians to crowdsource advice	Create a secure online portal for physicians to obtain colleagues' advice and opinions on a specific patient, identified through their national health insurance number.	1 (0.1)	0.4 (0.0)
Remote access to health care professionals for questions	Give patients the possibility to remotely contact health care professionals other than their own physician, to ask questions and receive responses in real time. This may take the form of a website, direct chat, or videocall.	5 (0.3)	8.9 (0.6)
Psychological support	Provision of psychological support to patients.	14 (0.9)	10.3 (0.7)
Helplines for medical information	Create helplines that offer information to patients regarding their illness, including answers to specific, urgent questions.	16 (1.0)	13.1 (0.9)
Helplines for psychological support	Create helplines that offer psychological support to patients. The hotlines may be staffed by health care professionals or trained peers with the same illness as the patient calling.	20 (1.3)	23.9 (1.6)
Coordinate patients' care network	**Close the edges between unconnected nodes in the patient's care network.**		
Joint consultations with many physicians	Patients will be able to have consultations with more than one physician simultaneously (e.g., GPs and different specialists).	13 (0.9)	5 (0.3)
Remote physician-to-physician communication	The patient's physicians will communicate with each other. For example, physicians of different specialties may contact each other to coordinate regarding the medications prescribed to the patient (to examine counter-indications due to one of the patient's illnesses, possible medication interactions, etc.), or they may exchange the results of examinations, lab tests and imaging. This does not refer to joint consultations in which the patient consults with multiple physicians simultaneously, but to communication between physicians in which the patient is not present. Communication also differs from physician-to-physician consultation, in that it refers to the bidirectional exchange of information about the patient, and not to a physician consulting another for a specialist opinion.	58 (3.8)	25 (1.6)
Remote physician-to-physician consultation	The patient's physician will consult with a specialist regarding the patient's case, either to spare the patient an additional consultation with a specialist, or because the specialist may be otherwise inaccessible to the patient (e.g., consulting with an international expert on the patient's condition). The physician may contact the	35 (2.3)	25 (1.6)

	specialist via an online platform and share patient data with consent (e.g., test results, the recording of the physical examination or the entire consultation between the patient and their own physician).		
Alert patients when their physicians communicate on their case	When physicians communicate on their common patient, the patient will receive an alert.	1 (0.1)	0 (0.0)
Have a single health care professional as "point of reference"	Patients will have a specific, single health care professional (most often proposed to be the family physician, but also potentially a specialized physician or a nurse) who will manage and coordinate the care of their chronic illness(es), consult other physicians on behalf of the patient if necessary, and chaperone patients in solving any problems that may come up (e.g., in their interaction with medical laboratories).	20 (1.3)	13 (0.8)
Record-sharing between physicians	Physicians will share their records of their common patients.	2 (0.1)	5 (0.3)
GP performs physical examination in place of specialist	If the patient's specialist is difficult to access (e.g., because they are located in a different city), physical examinations can be performed by the patient's GP and communicated to their specialist, to facilitate teleconsultations with the specialist.	1 (0.1)	0 (0.0)
Copy all of the patients' physicians in emails	When a physician communicates with their patient by email, or when a lab sends patients their test results, all of the patient's physicians should be copied.	2 (0.1)	1 (0.1)
App that allows third parties to pick up the patient's medication	Create an app that allows third parties to pick up the patient's medication	1 (0.1)	1 (0.1)
Create online recommendation systems where physicians recommend their colleagues	Create online recommendation systems where patients can find more physicians that have been recommended by their current physicians	1 (0.1)	1 (0.1)
Record consultations	Be able to record consultations. The recording can be used to remind patients the information discussed in the consultation or it can be shared with another physician who can offer a specialized opinion on the patient's case.	2 (0.1)	0 (0.0)
Give GPs access to their patient's hospital records	Give GPs access to their patient's hospital records	1 (0.1)	0 (0.0)
Advocacy organizations facilitate patient-physician communication	Advocacy organizations could mediate patient-physician discussions online, to 'translate' patients' needs to medical language.	1 (0.1)	0 (0.0)

Labs send test results to patients and physicians	Labs send the results of the patient's test to the patient and directly to the physician. The results could also be sent to all of the patient's physicians, if they have multimorbidity.	23 (1.5)	13 (0.8)
Prescriptions sent from physician to pharmacy	Prescriptions (or notification of their extension/renewal) are sent from the physician directly to the patient's pharmacy of choice	17 (1.1)	11 (0.7)
Use a single, shared health record	Establish the use of a single personal health record per patient, accessible online by the patient and all their health care professionals upon authorization by the patient. Physicians will both read this record in consultations, and update it with new information (e.g., notes, lab and examination results, prescriptions) so that all information about the patient is stored in one place. This can enable continuity of care and synchronize care between different specialists. Some participants specifically refer to encouraging French physicians to use the Dossier medical partagé (the virtual, shared personal health record application available to patients in France through the national insurance system).	66 (4.3)	34 (2.2)
Enhance human intelligence	**Enhance human intelligence (of the patient or the physician) by using artificial intelligence tools that perform tasks complementary to human cognition.**		
Artificial intelligence tools for diagnosis	Automated tools based on artificial intelligence can support physicians in diagnosis (e.g., in the case of rare diseases which often take a long time to diagnose, partly because of poor physician knowledge).	3 (0.2)	1 (0.1)
Drug interaction checker	Automated tools that check for interactions between medications.	1 (0.1)	0 (0.0)
Symptom-checkers	Use symptom-checker websites.	8 (0.5)	5 (0.3)
Chatbots	Provide patients with chatbots to be used in-between consultations.	2 (0.1)	1 (0.1)
Adjust treatment using artificial intelligence	Use artificial intelligence algorithms to automatically adjust patients' medication dose(s) and send the updated prescription(s) by email.	1 (0.1)	0 (0.0)
Reminder tools	Provide patients with automated systems that remind them to take their medication, attend consultations or renew their prescription.	5 (0.3)	2 (0.1)
Automated just-in-time adaptive interventions	Adoption of real-time adaptive interventions (e.g., closed loop insulin delivery).	1 (0.1)	0 (0.0)
Support innovation implementation	**Support the implementation of the remote parts of blended care or other modifications suggested by participants.**		
Adapt physician billable hours	In the current health insurance system, physicians are compensated on the basis of consultations. This should be adapted to accommodate new forms of care such as asynchronous remote communication with patients.	3 (0.2)	1 (0.1)
Chaperone remote care implementation	Support patients to access and use remote care, such as by creating local telemedicine hubs (i.e., community centres or local medical cabinets equipped with the necessary equipment for remote care,	8 (0.5)	3 (0.2)

	such as monitoring devices the patient can use), or assigning staff to help patients.		
Ensure interoperability between health record software	Refers to making electronic health record software used by physicians compatible with the (national insurance-provided) personal health record, to enable and facilitate its use.	1 (0.1)	0 (0.0)
Fund remote care equipment for physicians	Fund remote care equipment for physicians so they are able to provide remote care services.	1 (0.1)	0 (0.0)
Allocate time for communication between physicians	Similar to scheduled consultations between patient and physician, specific time slots will be allocated for physicians to consult with each other on their common patients.	1 (0.1)	1 (0.1)
Provide patients with physicians' contact information	Patients should be given their physicians' contact information (e.g., phone, email).	3 (0.2)	1 (0.1)
Shared decision-making for remote care modalities	Inform patients about the pros and cons of the remote care modalities introduced in their care.	1 (0.1)	1 (0.1)
Allocate time for remote physician-patient communication	Specific time slots will be allocated for physicians to contact their patients who have initiated asynchronous communication (e.g., by replying to their emails or returning calls).	1 (0.1)	0 (0.0)
Expand functions of personal health records	Expand the functions offered by the patients' personal health records. Participants' suggestions include: the possibility to have teleconsultations via their personal account on the national health record website, visualizations of the evolution of their illness over time, and self-monitoring logs that can be shared with their physician.	4 (0.3)	1 (0.1)
Reimburse teleconsultations	Provide equal reimbursement for teleconsultations and in-person consultations.	4 (0.3)	1 (0.1)
Adapt teleconsultations for patients with hearing loss	Make teleconsultations accessible for patients with hearing loss, such as by providing simultaneous Sign Language translation.	1 (0.1)	0 (0.0)
Simplify remote monitoring tools	Make remote monitoring tools simple and easy to use for all patients.	1 (0.1)	0 (0.0)
Create thematic email accounts	Health care organizations and physicians can create different email accounts for different patient needs to streamline communications.	1 (0.1)	0 (0.0)
Provide self-monitoring tools	Provide self-monitoring tools that offer data summaries and visualisations, with the possibility to share the monitoring data with physicians.	11 (0.7)	9 (0.6)
Equate remote and in-person prescriptions	Medication prescriptions obtained remotely should have the same validity as those obtain in person (e.g., same duration of validity, ability to prescribe all medications remotely).	3 (0.2)	10 (0.7)

Consultation cap	Set a limit of patients per physician per day (except for emergency services) to allow for more in-depth and longer consultations.	1 (0.1)	0 (0.0)
Information and education	**Provide information and education to patients and physicians.**		
Targeted information dissemination	Push-content systems, such as newsletters, will offer information and advice targeted to the patient's illness. This may include news about research on their illness and information on emerging situations that can reassure patients, such as advice for coping with seasonal infectious illnesses for patients with a given chronic illness.	8 (0.5)	5 (0.3)
Online self-management or coaching modules	Coaching and synchronous or asynchronous online courses can provide non-pharmacologic self-management skills to patients, tailored to their illness. Suggested topics include patient education, pain management, exercise and stress management. Suggested formats include videos, live streaming, and apps. The online modules can be stand-alone, or they can be offered to patients after a few in-person sessions.	14 (0.9)	3 (0.2)
Interactive, illness-specific webinars	Refers to patients being able to attend online informational seminars on their illness led by specialists to whom they can also pose questions	5 (0.3)	5 (0.4)
Provide information on treatment options	Provide information about all available treatment options with their pros and cons to patients, to enable decision-making.	3 (0.2)	1 (0.1)
Create reliable websites offering an "illness overview"	Create reliable websites that provide an overview of all necessary information about an illness.	5 (0.3)	1 (0.1)
Specialist directory	Provide patients with a directory of specialists on their illness.	3 (0.2)	1 (0.1)
Add FAQ section to hospital websites	Add frequently asked questions (FAQ) sections to hospital websites to provide information to patients	1 (0.1)	0 (0.0)
Link GPs to resources via hospital information systems	Link general practitioners to resources via hospital information systems. Resources may include links to associations on specific diseases, etc.	1 (0.1)	0 (0.0)
Patient representative education	Remote education of patient associations or expert patients.	1 (0.1)	0 (0.0)
Physician education	Remote education of physicians.	3 (0.2)	5 (0.3)
Documentation	**Provide patients with documents related to their care using remote technologies.**		
Store information on patient's insurance card	Store important information on patients' insurance card. The idea is that as people carry their card with them most of the time, the information would be readily available at emergencies or for patients with memory impairment, and that it provides a practical way of accessing a patient's virtual prescriptions.	7 (0.5)	3 (0.2)
Regular patient briefing	Patients will regularly receive a written summary of their care (e.g., exam results, treatments tested, health events experienced).	2 (0.1)	1 (0.0)

Receive documents by email	Patient receives documents, such as summary reports of consultations, by email (except for prescriptions, lab test results and referral letters, for which separate codes were used).	17 (1.1)	23 (1.5)
Administrative acts	**Facilitate administrative tasks.**		
Replace insurance card with face recognition systems	Replace insurance card with face recognition systems.	1 (0.1)	0 (0.0)
Apply for reimbursement online	Facilitate application for reimbursement by giving patients the option to transmit documents online, instead of by post.	4 (0.3)	1 (0.1)
Change insurance and employment regulations	**Change regulations regarding the insurance coverage and employment of chronically ill people.**		
Eliminate required referrals	Patients will be able to have a reimbursed consultation with a specialist without a referral letter from their family physician. A referral letter is currently required in France to obtain reimbursement.	3 (0.2)	2 (0.1)
Allow remote work for chronically ill employees	Allow remote work for chronically ill employees.	2 (0.1)	0 (0.0)
Other	**Uncategorized codes**		
Wear masks in winter	Wear masks in winter to avoid infectious diseases (e.g., flu).	2 (0.1)	7 (0.5)

[a] Weighted data were obtained after calibration on margins for sex, age, and educational level by using data from a national census describing the French population with chronic illness.