

Unintended consequences of patient online access to health records: a qualitative study in UK primary care

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Research Article

Keywords: EHR, Unintended consequences, Digital first primary care, Digital health, qualitative interviews, electronic health records

Posted Date: January 13th, 2022

DOI: <https://doi.org/10.21203/rs.3.rs-1256673/v1>

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Version of Record: A version of this preprint was published at British Journal of General Practice on October 31st, 2022. See the published version at <https://doi.org/10.3399/BJGP.2021.0720>.

Abstract

Background

Health systems around the world are seeking to harness digital tools to promote patient autonomy and increase the efficiency of care. One example of this policy in England is online patient access to full medical records in primary care. Since April 2019, all NHS England patients have had the right to access their full medical record prospectively, and full record access has been the “default position” since April 2020.

Aim

To identify and understand the unintended consequences of online patient access their medical record.

Design and Setting

Qualitative interview study in 10 general practices in South West and North West England.

Method

Semi-structured individual interviews with 13 patients and 16 general practice staff with experience of patient online access to health records.

Results

Online access generated unintended consequences that negatively impacted patients’ understanding of their health care, for example patients discovering surprising information or information that was difficult to interpret. Online access impacted GPs’ documentation practices, such as when GPs pre-emptively attempted to minimise potential misunderstandings to aid patient understanding of their health care, in other cases, negatively impacting the quality of the records and patient safety when GPs avoided documenting their speculations or concerns. Contrary to assumptions that practice workload would be reduced, online access introduced extra work, such as managing and monitoring access and taking measures to prevent possible harm to patients.

Conclusion

The unintended consequences described by both staff and patients show that to achieve the intended consequences set out in NHS policy additional work is necessary to prepare records for sharing and prepare patients about what to expect. It is crucial that practices are adequately supported and resourced to manage the unintended consequences of online access now that it is the default position.

How This Fits In

Previous studies of patient online access to their medical records have noted a range of concerns about potential unintended consequences. This study reports real-world experiences of the consequences of online access. We identified unintended consequences that impacted patient autonomy and GP documentation practices, and also increased workload through providing access while avoiding harm to patients. It is crucial that practices are adequately supported and resourced to manage the unintended consequences of online access now that it is the default position.

Introduction

Political, economic, and social pressures are driving patient access to health records globally.¹⁻⁴ Health care systems in a range of countries make medical records accessible to patients in some form, although there is considerable variability in what and how information is available to patients.⁵

Online patient access to their medical records (henceforth, online access) satisfies the moral argument that the information rightly belongs to the patient and so should be accessible to them.^{1,6} More instrumentally, online access is intended to promote patient autonomy and enable patients to take greater control of their health, in parallel to increasing the efficiency of care and delivering reductions in GP practice workload.⁷⁻¹² However, these are relatively new roles for medical records to perform in contrast to their traditional roles supporting clinicians in the care of patients and providing evidence for legal matters, audit and research.¹³

In the UK, online access to summary information in primary care records has been available to patients since 2015 and, before this, the right to a copy of one's medical record was part of data protection legislation (typically a print copy). The NHS Long Term plan created the right for patients to access 'digital first' primary care by 2023-24 which, since April 2019, has meant all patients registering with a GP practice could have full record access prospectively, and full record access has been the "default position" since April 2020.¹¹ Users of the NHS app (or similar apps) will be able to view new entries to their health record from December 2021 or early 2022.¹⁴

NHS England patients can be given online access by registering for 'online services' at their GP practice. (Online services also includes other linked services, such as booking appointments and ordering repeat prescriptions, that are not the subject of this study). Patients can access their records online through various providers.¹⁵ Access is available at two levels: a 'detailed coded record' (DCR) and a 'full record'. DCRs contain information about a patient's allergies, immunisations, medications, and test results, as well as coded problems, diagnoses, and procedures, although what is made available from this list varies between practices. Full records contain the DCR, plus free-text clinician consultation notes and other documents such as hospital letters. However, results from recent GP Patient Surveys show that only 7% of patients said they were using online services to access their medical records.^{16,17}

Studies of online access to medical records have found some evidence it can improve health outcomes and patient safety.^{6,18} Studies have also found that patients have used online access to better

understand and control their health, for example, by allowing them to better prepare for subsequent consultations and correct errors,^{18–23} while finding the technology “convenient, useful, useable and flexible”.^{24, 25}

Evaluations of digital health tools have found that their promise is not always delivered however and real-world implementation frequently produces unintended consequences.^{26–28} That is, positive or negative effects that were not intended at the outset, but which often occur when adopting novel technologies.²⁹ Possible unintended consequences of online access include concerns about confidentiality and risk of patient coercion,^{3, 30} patient confusion and anxiety,^{3, 6, 31} as well as the creation of additional clinician workload²⁵ and widening of health inequalities.³² However these are often speculative and hypothetical concerns, with unclear evidence they are realised in practice.³

The aim of this study was to identify and understand the unintended consequences of online access to health records experienced by patients and practices, to inform guidance on mitigation of those consequence at practice and policy levels.

Methods

Semi-structured individual interviews with patients and staff from GP practices in South West and North West England in 2019 and 2020 examining the unintended consequences of online access to health records.

We define unintended consequences in contrast to the intended consequences set out in policy documents. NHS England policy documents suggest that there are two main intended consequences of providing streamlined access to information about one’s health through online access to health records:^{7–11}

Intended consequence 1: Improve autonomy and enable patients to take greater control of their health. Providing “information about their condition and history” to support more “personalised care [...] wellbeing and independence”,⁸ helping patients “manage [their] own health and care better” and enabling “more informed discussions and genuine involvement in decisions about our health and care.”⁷

Intended consequences 2: Improve the efficiency of care or improve practice workload. Creating “significant increases in productivity that far outweigh the initial investment” through, for example, “reductions in ad hoc contacts with some patients”⁷ and enabling “care to be designed and delivered in the place that is most appropriate for [patients, clinicians and their carers].”¹⁰

In this study consequences are labelled as unintended if they did not fall under the intended consequences given above. Unintended consequences could be positive or negative or could be anticipated or not.

Sampling and Recruitment

Research active practices in 8 Clinical Commissioning Group (CCG) areas in the South West and North West were provided with study information by the NIHR Clinical Research Network. Expressions of interest were received and practices were purposefully selected to ensure a diverse mix in relation to size, urban/rural location, and indices of area-level socioeconomic scores for the practice population.³³

Practice staff were recruited through the practice manager or research lead. Patients were eligible to take part if they were registered for online services, or were known to staff as having requested full-record access. When large numbers of patients met these criteria, the set of those invited was targeted by age, ethnicity, and long-term condition to try to maximise diversity. Eligible patients were sent invitation letters by participating practices or were opportunistically provided with study information by clinical staff.

The concept of 'information power'³⁴ informed analysis, sampling and participant recruitment, which were conducted in parallel to allow sampling to be refined as the project developed. Information power is a guiding principle in qualitative research, suggesting that studies with broad aims and exploratory analysis may need larger samples, while smaller samples can be sufficient if data is focused and if participants have rich experiences relevant to the research question.

Data collection

Topic guides were developed by the study team and informed by a stakeholder workshop held in 2018 to explore possible unintended consequences of digital health technology.^{35,36} Topic guides were refined iteratively as interviews and preliminary analysis progressed. Interviews were conducted between February 2019 and January 2020 by [AT and RM] (face-to-face or by telephone) and lasted 20-60 minutes.

Analysis

Interviews were fully transcribed and coded using QSR NVivo 12 software. Thematic analysis³⁷ was used to explore staff and patients' descriptions of the consequences of online record access. Initial noting of ideas was followed by line-by-line examination and inductive coding by AT and RM. The first 3 transcripts were coded independently [JH AT] and discrepancies discussed to contribute to the generation and refinement of codes to maximise rigour. The coding frame was further refined through discussion with the whole study team, including PPI contributors. Themes were examined to determine whether the consequences being described were in line with the intended consequences outlined above, or were unintended consequences [JH RM DR AT]. These were again refined by discussion between [JH RM DR AT], PPI contributors, and the study team to ensure credibility and confirmability.

Results

Practice and participant characteristics

Interviews were conducted before April 2020, so practices that participated were not yet obliged to offer full-record access to existing patients. Characteristics of the 10 practices are shown in Table 1 and 29 participants interviewed in Table 2.

Table 1
Practice characteristics

Site	Patient list size*	IMD quintile**	Location	Level of patient online access to health records***	No. staff interviewed	No. patients interviewed
1	Medium	5	Urban	DCR	1	1
2	Small	5	Urban	DCR	2	5
3	Medium	5	Rural	DCR	2	0
4	Large	2	Urban	Full record	4	2
5	Medium	5	Urban	DCR	0	2
6	Small	5	Rural	Full record	0	1
7	Small	5	Urban	DCR	1	0
8	Large	2	Urban	DCR	2	0
9	Medium	2	Urban	Full record	1	0
10	Small	4	Urban	DCR	3	2
* small < 10,000; medium 10-15,000; large 15,000+						
** IMD =Practice location Index of Multiple Deprivation. 1=more deprived, 5=less deprived. (https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019)						
***DCR= Detailed Coded Record						

Table 2
Participant characteristics

Characteristics of patients	n = 13
Sex	
Female	9
Male	4
Age	
30-54	2
55-64	9
65+	2
Ethnicity	
White British	13
Characteristics of GP practice staff	n = 16
Sex	
Female	8
Male	8
Staff role	
GP	10
Administrative/Managerial	6
Average no. years GP qualified	21

Table 1: Practice Characteristics

Table 2: Participant Characteristics

Findings are presented according to the pre-defined intended consequences (see above), illustrated with anonymised verbatim quotes. We note how the intended consequences were achieved, before considering unintended consequences.

Intended consequence 1: Improve autonomy and enable patients to take greater control of their health

Staff and patients described online access primarily improved patient autonomy by providing a more convenient way for patients to view information about their health care. Patients reported that this enabled patients to check test results, treatment plans or remind themselves about the content of

previous consultations or occasionally equipped them to challenge their GP or take more control in subsequent consultations. For example, as one patient explained:

“my last consultation [...] I just took him [the GP] a list of about 15 questions about my condition [... record access has] certainly helped me to ask more questions or to know a bit more about [my condition]” (Patient-2, Practice-6)

Unintended consequences

Patients and staff highlighted unintended consequences of online access that challenged the intended goal of improving patient autonomy, in the sense of supporting patient ‘well-being and independence’ and enabling their ‘genuine involvement’ in their health and care (see the definitions of intended consequences above). First, some patients described discovering information in their health records that had surprised and distressed them, and which their original consultation had not prepared them for.

“I went onto the patient record [...] to look for if any of the blood test results had come back [...and it] said, ‘urgent referral request: suspected breast cancer’. [...] You’re instantly like, Christ! The doctor thinks that I’ve got breast cancer.” (Patient-1, Practice-2)

GPs and administrative and managerial staff had little awareness of whether patients experienced this kind of unintended consequence, despite their *concern* that online access could cause patients distress if they learned something of which they were previously unaware.

Second, patients noted online access did not increase autonomy, in the sense that simple access to information did not necessarily equate to greater involvement or better management of their own health and care. Some patients explained that “sometimes too much information can be unhelpful.” (Patient-1, Practice-2) or that “a little bit of knowledge is a dangerous thing” (Patient-2, Practice-10), especially if they did not have sufficient context to interpret it and searched online about the “disadvantages or drawbacks” (Patient-2, Practice-6) of a condition. One GP described a conversation with a patient who no longer wanted online access because they did not want to read about their growing medical problems.

“There were two or three things that [the patient] had to remember [following the consultation] and so for me it’s always been natural, ‘just go online and check so you can remind yourself’. [...] And she was like ‘oh, I don’t really look at my records anymore’, I said, ‘why not?’, ‘Well, because I don’t want to... I’m scared of seeing something that means I’ve got another problem on top’” (GP-1, Practice-9)

Third, GPs suggested that information in the record was not tailored to the needs of patients which could lead to misunderstandings or misinterpretation. For example, GPs noted that patients could struggle to interpret test results, particularly when clinically unimportant information was also visible. GPs thought that their own documentation practices could be a source of difficulty for patients, explaining that consultation notes were written using abbreviations, jargon, and in a time-constrained context where accuracy of spelling was not always prioritised.

“there’s a heck of a lot of spelling mistakes we make in our notes. [...A patient] who requested all her notes, I did have that conversation with her, I said, ‘there will be lots of spelling mistakes and things’ and forewarned her.” (GP-1, Practice-4)

Fourth, online access could have wider medico-legal or patient safety consequences when concern about how information might be interpreted by patients affected the content of consultation notes. For example, some GPs described the difficulty of recording their concerns in notes that would be visible to patients.

“[if] you’re worried about domestic violence or drug use or something like that and you’re not necessarily firm enough, you might have tried to explore it [... but the patient is] coming in and doctor hopping [...] you can put on a note [in the record] to that effect [...] but you know I’d be very wary of doing that now. I might go and phone the [other] doctor myself if I know they [the patient] were coming in and have a chat with them [the doctor]. But I definitely feel you have to be careful about what you’re putting down in the record” (GP-1, Practice-10)

Notes about possible diagnoses or GP “gut feelings” were described in similar terms: such speculation was thought to leave “hostages to fortune” (GP-3, Practice-1) if made visible to patients, particularly when the pressures of consultations meant that it was not possible or practical to discuss an issue thoroughly with them. In these cases, speculative but important information was either not documented or shifted to less formal channels.

GPs suggested that mitigating all four kinds of unintended consequence could be achieved through their already cautious and transparent documentation practices. GPs described how their notes were “factual” (GP-1, Practice-4), “objective [... and] defensive” (GP-2, Practice-2) to minimise potential issues for patients viewing them. One GP explained how they write notes without jargon to aid patient understanding.

“[For a female patient] for instance, [the] instructions I wrote was written in a way so I knew, if she reads it, she will be able to understand, rather than using shorthand”. (GP-1, Practice-9)

Another GP described how they had adapted the terminology they use: avoiding “normal” in test results and instead calling statistically abnormal but clinically normal results “satisfactory” (GP-1, Practice-2) to avoid confusion. GPs also gave examples of writing notes “transparently” and “jointly” with patients by explaining to patients what is being documented as they write it.

“I do transparent practice, so [I] verbalise what I’m finding with patients, I verbalise what I think is going on in my records, I will only put ‘my impression is this’. [...] so I’d hope that you’re not going to get things back in your face”. (GP-1, Practice-8)

Intended consequences 2: Improve the efficiency of care or improve practice workload

The primary way that staff found patient online access to their health records improved practice workload was by shifting the responsibility for producing copies of medical records. Instead of practices

printing out copies (possibly multiple times), staff and patients highlighted the efficiency of allowing patients to extract information themselves when they pleased.

Unintended consequences: efficiency of care and workload

Patients appreciated the convenience of being able to view their record when they pleased, but beyond this they did not comment on the efficiency of the care they received. Consequently, the unintended consequences below focus on staff experiences of five kinds of addition to practice workload.

First, the preparation of records before giving patients access added to staff workloads. Preparing records included tasks such as redacting sensitive information (that is, information that “would be a risk of harm to [...] the patient or somebody else” (Admin-1, Practice-4)) and references to third-parties (such as individuals other than the patient who can be identified from information in the record).

“We certainly all anecdotally talk about the work that it’s created with many of the admin staff having to go through and take out third-party references and things. Giving patients ownership over their health can be a good thing, but it can also generate work in other ways.” (GP-1, Practice-4)

Although software was sometimes available to help, this “only solve[d] part of the problem.” (Admin-1, Practice-7) and manual checking was often needed.

Second, online access increased workload when clinical staff provided support to patients requesting access. In these cases, supporting and “preparing patients” (GP-1, Practice-9) was necessary to help patients know what to expect, and avoid misunderstanding and surprises. Some GPs provided patients with information leaflets or questionnaires, but there were also instances where GPs had arranged a face-to-face consultation with particular patients, so they could go through important parts of the record together.

“I had a patient who had quite a lot of terrible things [happen] to her in her childhood [...] she wanted online access and so when she requested it [...] I said, ‘You are going to have online access. What I think would be good if we go through your record now’. [...] The record was] not that massive and I just went through the problem codes with her so that she could see what they were and that they made sense to her.” (GP-2, Practice-4)

Third, additional workload was also generated when managing access to records of teenage children (around 13 years). For example, situations that generated extra work included: practices being asked to redact comments in the child’s record that parents do not want the child to see (or vice versa); allowing access for parents who have separated; and parents requesting access to a child’s record. As well as creating extra administrative work, some situations also meant navigating tricky conversations with parents and children. For example, at one practice where parental access ended when a child turned 13 years of age:

“There have been a couple of occasions when that’s actually been really quite difficult, where the kids find themselves in a difficult position of parents saying, ‘well why can’t I have access to the notes?’ And you say, ‘well it’s set up for your child to say whether you have this or not’ and the parents will say, ‘well they won’t mind, that will be fine, of course it will’, the child is there and you can see the child squirming [...] If you know the situation, you can actually engineer [a way out of] it, but sometimes that can be quite noisy and quite difficult.” (GP-1, Practice-2)

Fourth, staff recognised risks around online access for patients experiencing domestic violence and abuse and described the difficulty of ensuring that access would not cause harm if perpetrators viewed their partner’s record. An unintended consequence of online access therefore was the additional work undertaken by staff to minimise harm, such as, considering requests on a case-by-case basis and attempting to see the patient alone, face-to-face, to confirm access requests were from them and for them.

“[domestic violence and abuse is] one of the reasons why the process [to get access] is a bit more long-winded now [... a consultation in advance allows] the GP to speak to the patient and that’s kind of why we want the face-to-face because they can be alone in the room [...] the GP just needs to make sure that they actually want the access themselves and it’s for them.” (Admin-1, Practice-4)

Fifth, once online access was available, staff described unintended additional workload from managing and monitoring access, such as queries from patients challenging information or finding errors in their record that required correction. Staff noted that genuine errors were typically easy to amend, whereas patient disagreement with otherwise appropriate codes had the unintended consequence of generating “difficult discussions” around topics such as obesity.

“people don’t like to see things that may be negative about themselves [...] we do tend to find it’s the obesity stuff that they [patients] object to” (Practice Manager, Practice-10)

Although Online access generated practice workload in a range of ways, staff sometimes down-played the impact of online access because access requests were processed on an *ad hoc* basis, and therefore spread out, and patient uptake was relatively low at the majority of practices.

“I didn’t really see that it was going to be that great a change and in our experience it hasn’t been that great a change. It’s still a very low number of patients that want to see their notes and records, or have access to them, in fact we had difficulty convincing patients to sign up.” (Practice Manager, Practice-4)

Discussion

Summary

The intended consequences of online access in policy documents are to improve patient autonomy and control of one’s health, and improve the efficiency of care and practice workload. However, the implementation of online access is more complex than the intended consequences would suggest. Online

access generated unintended consequences that negatively impacted patients' control over and understanding of their health, such as when patients discovered surprising information or information was difficult to interpret. Online access impacted GPs' documentation practices, in some cases potentially aiding patient autonomy such as when GPs pre-emptively attempted to minimise potential misunderstandings, in other cases, negatively impacting the quality of the record when GPs avoided documenting their speculations or concerns, which could have negative medicolegal and patient safety consequences. Contrary to assumptions that practice workload would be reduced, online access introduced necessary extra work, such as managing and monitoring access and taking measures to prevent possible harm to patients.

Comparison with existing literature

Studies of online access to medical records have found patients have used them to understand their health and take greater responsibility for their care,¹⁸⁻²³ and found the technology convenient and useful²⁴ however our findings provide a more nuanced understanding.

Previous research has highlighted potential unintended consequences of online access. There are well-known concerns around confidentiality and risk of patient coercion,^{3,30} patient confusion and anxiety,^{3,6,31} as well as the creation of additional clinician workload²⁵ and widening of health inequalities.³² However these are often hypothetical concerns, with unclear evidence they are realised in practice.³ A key strength of our research is that we report the actual experiences of patients and staff using online access.

Strengths and limitations

This study has identified unintended consequences by drawing on the experience of online access by patients and practice staff, rather than their concerns about potential unintended consequences.

Patient experiences of unintended consequences were limited because practices had low numbers of patients using record access. Staff had experienced minor impacts from the increased workload that providing access requires and had minimal experience of patient harm resulting from online access (although we did find some examples from patients of significant, distressing, surprises). Lack of examples of patient harm should be taken as an absence of evidence, not evidence of absence.

Many practices were not able to easily identify patients who used their online access. Registration for online services is a blunt tool since registration does not entail use. Furthermore, registration is necessary for other linked services (e.g. appointment booking and repeat prescription ordering) that may be the main reason for patients registering.¹⁶ Future research must carefully consider, in discussion with practices, how to identify patients using online access.

Patients who agreed to participate were mostly middle-aged and all white British. More generally, the 2020 GP patient survey found that older people were less likely to use online services.¹⁶ Findings should be interpreted considering these limitations. Invitations to participate were in English, sent by post by GP

practices, and required individuals to respond to the University researcher, which may have introduced socio-cultural barriers for some communities. Future research could recruit in collaboration with community groups rather than GP practices to improve recruitment diversity, although it would be essential to ensure reciprocal benefits to avoid gatekeeper fatigue.

Implications for research and practice

Table 3 outlines the unintended consequences we identified and offers mitigation guidance for clinicians and practice managers.

Table 3
Patient online access to health records guidance for clinicians and practice managers

Potential unintended consequences	Mitigation
<ul style="list-style-type: none"> • Distress for patients at discovering unknown information in their record. • Additional workload for staff supporting patients in order to prepare them for what to expect from online access. 	<ul style="list-style-type: none"> • Offer consultation to patients who you are concerned may be surprised or distressed by parts of their record. • It may also be prudent to verbally summarise what is being documented during consultations to reduce the risk of future surprises or distress.
<ul style="list-style-type: none"> • Non-patient friendly information in records. For example, jargon, abbreviations, spelling mistakes, lack of context, leading to offence, misinterpretation or misunderstanding. 	<ul style="list-style-type: none"> • Where possible, clinicians should aim to reduce the use of jargon that may offend or confuse. However, it is imperative that the content of patient notes are kept as accurate as possible. Improving understandability for the patient must not compromise a high-quality of care. • Use texting or email to communicate reliable websites for information about conditions and treatments.
<ul style="list-style-type: none"> • Clinician hesitation to document speculative concerns or diagnoses or third-party information in records that are shared with patients. 	<ul style="list-style-type: none"> • Clinicians should continue their objective and factual documentation practices.
<ul style="list-style-type: none"> • Additional workload to redact sensitive or third-party content. 	<ul style="list-style-type: none"> • Software to automate these tasks is available, but manual checking may still be required. • It may be practical to have a staged rollout of online access, as patients individually request it, to spread the workload over a longer period of time.
<ul style="list-style-type: none"> • Additional workload from managing more complex situations, for example: parent/teenager access, or individuals experiencing domestic violence and abuse. 	<ul style="list-style-type: none"> • It is recommended that complex situations are dealt with on a case-by-case basis before online access is provided. Where possible, this should involve a multidisciplinary team. • In the case of parent/teenager access, depending on the competence and capacity of the young person, consent must be gained before releasing notes to parents.
<ul style="list-style-type: none"> • Additional workload from patients querying/challenging notes and correcting errors. 	<ul style="list-style-type: none"> • Corrections or qualifications should be welcomed. Practices should expect that a minority of patients will present with questions regarding the content of the notes.

Table 3

All the measures identified in Table 3 require extra work on behalf of practices and there is a clear up-front cost to preparing records and supporting patients to access their records. The accumulation of individually minor tasks may pose a more significant challenge as online access is scaled-up, however, some workload may diminish over time. For example, it is a one-time task to redact sensitive content or correct an error highlighted by a patient. Providing access as patients individually request it spreads this workload over a longer period making it potentially easier to absorb.

Making records accessible to patients raises questions about how they can best serve both clinicians and patients, when traditionally the primary purpose of medical records has been to support clinicians in the care of patients.¹³ The unintended consequences described by both staff and patients show that to achieve the intended consequences set out in NHS policy additional work is necessary to prepare records for sharing and prepare patients about what to expect. It is crucial that practices are adequately supported and resourced to manage the unintended consequences of online access now that it is the “default position”.¹¹

Declarations

Funding

The DECODE study is funded by National Institute for Health Research (NIHR) School for Primary Care Research and supported by NIHR Applied Research Collaboration West (NIHR ARC West). This work was also supported by the National Institute for Health Research (NIHR) Greater Manchester Patient Safety Translational Research Centre (award number: PSTRC-2016-003). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Ethical approval

The study received approval from North West - Haydock NHS Research Ethics Committee (Ref: 18/NW/0625).

Competing interests

None to declare.

Acknowledgements

The authors would like to thank all the participants in this study, Bob Golding for his PPI input over the course of the study, the NIHR Clinical Research Network for adopting the study on the NIHR portfolio, and the NIHR SPCR for funding the research. Sue Ziebland and John Powell are NIHR Senior Investigators. Jeremy Horwood and Gemma Lasseter are members of the NIHR Health Protection Research Unit in Behavioural Science and Evaluation at University of Bristol.

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