

Supplementary Appendix S1

GP and Patient topic guides

Topic guides for the DECODE study covered three technologies: online consultations, patient online access to medical records, and smartphone apps to help manage long-term conditions.

Only results about online consultations are reported in this article.



DECODE: unexpected consequences Of Digital health

GP Practice Staff Interview Topic Guide

Introduction

- Policy (e.g long term plan) advocating use of digital health tools to improve patient autonomy, practice efficiency, quality of care.
- However their use could lead to unexpected consequences (positive and negative).
- So our aim is to improve the appropriate adoption of digital health tools in primary care by identifying and understanding their unexpected consequences.
- Not about evaluating a particular system, but understanding the impacts of three *kinds* of technology.
- For example, consequences for: patient's relationship with primary care, patient safety, and medical decision-making, as well as clinical practice, workflow and workloads.

Telephone interview introduction and consent

- Introduction/aims/consent – voluntary participation, audio record, anonymous quotes
- Switch audio recorder on - For the audio recording, can I check that:
 - You read and understood the study information sheet?
 - You know that taking part in the interview is voluntary and you are free to stop the interview at any point and you may skip questions you would prefer not to answer?
 - You agree to our conversation being audio recorded?
 - You understand that quotations from the interview may be used to illustrate our findings but it will not be possible to trace who said them?
 - You understand that the information collected may be used to support other research in the future, and may be shared anonymously with other researchers?
 - You understand that authorised and responsible individuals may look at sections of the study data, to carry out monitoring for the research sponsor?
 - You agree to take part in the study?

Warm up

1. What is your role in this practice, and how long have you been working here?
2. [if GP] How long have you been a GP
3. At your practice you use [COMPLETE ACCORDING TO PRACTICE INFO], which of these have you been involved with or seen the consequences of?
 - Smartphone apps / EHR access / Online consultations
4. What was your involvement in the practice's adoption of these technologies?

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- Decision-making?
- Implementation / training?

ONLINE CONSULTATIONS

Intended Consequences

- **Signpost to self-care and alternative care**
- **Improve patient access to care**
- **Improve efficiency of care/practice workload**

- Can you briefly talk me through how the system works in the practice?
 - How long has it been up and running?
 - What is uptake like?
 - What information do you get from patients?
 - How does it fit into your day to day workflow?
 - Overall is this a welcome development in your practice?
- What were the challenges that you wanted the system to address?
 - E.g.
 - Increased efficiency / improved workflow
 - improved patient autonomy
 - To address high demand for face to face appointments
 - Keeping on top of advancing technology
- What were the benefits you hoped the system would achieve?
- How well has it achieved those benefits?
 - E.g. time to see benefits,
 - E.g. magnitude of benefits
 - Do you think there are any cost savings or losses? - Why?
- Besides those benefits, what other consequences were you expecting?
 - Can be positive or negative
 - Has anything been traded off or placed lower down in the practices' priorities by offering online consultations?
- Have there been any additional unintended benefits that you weren't expecting?
 - E.g.
 - For staff/ the practice
 - For patients
 - Have you seen consequences for:
 - workload and how you manage your time [flexibility, learning curve, confidence]
 - patient safety
 - the way you communicate with patients / your relationship with patients

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11. Have there been any unexpected challenges or downsides?
- E.g.
 - For staff/ the practice
 - For patients
 - On workload and how you manage your time [flexibility, learning curve, confidence]
 - On patient safety
 - On the way you communicate with patients / your relationship with patients
12. [if GP] How does performing online consultations affect your relationship with patients?
- E.g. how you communicate with patients
 - In how you respond initially
 - In how you approach subsequent phone or f2f consultations
 - [either way] Did you expect that?
 - How does it help, or hinder, you to manage patient care?

In policy documents the *intended* consequences of online consultation systems are that they will: Signpost to self-care and alternative care, Improve patient access to care, Improve efficiency of care/practice workload...

13. ...In your use of the system, have there been any *unintended* consequences of introducing online consultations?
- E.g. Positive / Negative?
 - How have staff used the system in unexpected ways?
 - How have patients used the system in unexpected ways?
 - How have staff or patients modified the system to better meet their needs?
 - Has the use of the system thrown up any other surprises?
 - Impact on workload
 - Trade off's

ACCESS TO MEDICAL REDORDS

Intended Consequences

- **Improve patient autonomy**
- **Promote control of own health/health behaviour**
- **Improve efficiency of care/practice workload**

14. Can you briefly talk me through what patients do to get online access to their records?
- What level of information can they access?
 - Do you restrict patients' access to any parts of their EHR?
 - Do you think there are any cost savings or losses? - Why?
 - Overall is this a welcome development in your practice?
15. Why is online record access set at the current levels?
- What challenges does online record access address?

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16. What benefits were you anticipating from allowing patients to access their records online

- For the practice
- For patients

17. How well has it achieved those benefits?

- E.g. time to see benefits
- E.g. magnitude of benefits (for patients or practice)
- To what extent has EHR access improved patient autonomy, or promoted patients' control of own health/health behaviour?
- How has the system improved the efficiency of care/practice workload?
- Has anything been traded off or placed lower down in the practices' priorities by giving patients record access?

18. Besides those benefits, what other consequences were you expecting?

- Can be positive or negative
- Has anything been traded off or placed lower down in the practices' priorities by offering online consultations?

19. What were the key issues that you took into account before giving patients online access?

- What, if any, negative consequences were you concerned about before implementing online access? – Did they materialise?
 - E.g.
 - Patient coercion within potentially abusive relationships.
 - Recording early concerns about abuse or maltreatment (e.g. child protection, vulnerable adults).
 - Patients informing the practice that their records are wrong/ inaccurate.
- How well equipped are patients to understand their EHR?

In policy documents the *intended* consequences of online record access are that the it will: Improve patient autonomy, Promote control of own health/health behaviour, Improve efficiency of care/practice workload...

20. ...As a result of the practice offering patients online access to their records, have there been any additional unintended benefits that you weren't expecting?

- For staff/ the practice
- For patients
- On workload
- On patient safety
- On the way you communicate with patients / your relationship with patients

21. Have there been any unintended challenges or downsides?

- For staff/ the practice
- For patients
- On workload
- On patient safety
- On the way you communicate with patients / your relationship with patients

22. [QUICK EXIT QUESTION] What other effects has patient online access had?
- E.g.
 - On your workload
 - On your relationship with patients
 - On how you write notes
 - Were these effects expected or unexpected?
23. How else does patient online access to records affect your workload?
- E.g.
 - Impact on work practices, workload, consultation time?
 - Were these effects expected or unexpected?
24. How does patient online access to records affect your relationship with patients?
- Does it help patients with self-management of their conditions at all?
 - Were these effects expected or unexpected?
25. What effect does patient online access to EHRs have on, for example, how notes are written?
- Would patients having access to their records affect your decisions about what to record?
 - Does the possibility of a patients' partner or carer seeing the record affect your decision?
 - Were these effects expected or unexpected?
 - Are these effects welcome, or do they need to be mitigated? (How?)
26. [Frame in terms of the challenges and expected benefits] Have there been any unintended consequences of introducing online consultations?

SMARTPHONE APPS FOR MANAGING LONG-TERM CONDITIONS

Intended Consequences

- **Identify risks or facilitate health**
- **Self-track bodily functions and activities**
- **Promote self-management/behaviour change**
- **Improve efficiency of care/practice workload**

27. What experience do you have of working with patients who use smartphone apps for managing their long term conditions?
- What apps?
 - What long term conditions do these patients have?
28. Have you ever recommended an app to patients, or have patients shown you apps they already use?

- GP Recommended prompts:
 - Is app use something you are keen to encourage?
 - Where do you hear about apps (orcha.co.uk, NHS library?)
 - Do you see it as part of your role to check how secure, trustworthy etc an app is before discussing with a patient? (How do you know? – EB, secure etc)
- Patient initiated prompts:
 - Roughly how often has this happened during the last 6 months in your practice?
 - Thinking about the most recent example:
 - Do you know why they decided to use it?
 - What did you do when shown an app?
 - When would you encourage or dissuade patients from using certain apps?

29. What benefits are you hoping to achieve by recommending apps?

- Identify risks or facilitate health?
- Self-track bodily functions and activities?
- Promote self-management/behaviour change?
- Impact on communication with patient ?
- Improve efficiency of care/practice workload?

30. Did those expected benefits materialise?

- Positives?
- Negatives?
- Does app use affect how often you see patients with long-term conditions? – is that good or bad?

In policy documents the *intended* consequences are that apps will: Identify risks or facilitate health, Self-track bodily functions and activities, Promote self-management/behaviour change, Improve efficiency of care/practice workload...

31. ...In your experience of recommending or encountering patients who use apps to help manage their long term condition, have there been any *unintended* consequences of using it?

- Have you or the patients you work with encountered any difficulties?
- How have these been addressed?
- Have you had any surprises from patients using apps?
- Impact on work practices, workload?
- Patient safety?
- In what ways do you think the app affected how patients view their condition?

32. How do you integrate app data into your consultations?

- Do patients bring lots of data with them?
- How do you manage this within the consultation?
- How has it affected your decision-making? – is it actionable data?

- Impact on dr-patient relations
- How do you record these consultations in patients' notes?

CLOSE

33. Thinking about the role of these technologies in primary care, do you think there are (or should be) more pressing priorities for the practice? What are they?
34. How do the expectations of “digital-first primary care” in the NHS long term plan and new GP contract influence the practice’s strategy around new technologies?
(Repeat prescriptions electronically from April 2019. Digital access to their full records from 2020. Web and video consultations by 2021.)
35. Apart from those discussed already are there any other examples of new tech in primary care have not worked as expected in improving care or practice efficiency?
36. Do you have anything to add before we finish the interview?



DECODE: unexpected consequences of Digital Health

Patient Interview Topic Guide

Introduction

- Policy advocating use of digital health tools to allow patients to have a central role in decisions about their medical care, have better and easier access to their GP, and also on the practice-side, free up GP time and improve the quality of care.
- However their use could lead to unexpected consequences (positive and negative).
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Square brackets – prompts to remind interviewer of context for question, not for interviewees.

1. How is your health in general?
2. Are you currently being treated for any health problems?
3. Can you tell me what technologies you use to manage your health:
 - Smartphone apps for managing long-term conditions
 - Alternatives to face-to-face consultations including online consultations
 - Patient online access to their medical records

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ONLINE CONSULTATIONS

Intended Consequences

- **Signpost to self-care and alternative care e.g. pharmacies**
- **Improve patient access to care e.g. rather than having to phone the practice to get an appointment**
- **Improve efficiency of care e.g. may not need to wait for a face-to-face appointment**
- **Free up GP time e.g. reduction in the demand for face-to-face appointments**

4. Why did you decide to use the system initially?
 - [was it a genuine alternative route or 'forced' route to GP services]
5. How often have you used it?
 - [Regularly; Particular time of day]
6. What have you used it for?
7. What were you hoping to get out of using it?
 - [What benefits were expected - e.g. Convenient to complete, quicker response, reducing unnecessary travel.]
8. How well did the system meet your needs?
 - Did it take some getting used to? – Which parts? Why? How long until mastered?
 - Did you encounter any difficulties? – How did you deal with them?
 - Were there any concerns you had about using the system?
 - [E.g. Security / Privacy / Confidentiality]
9. Thinking about the most recent time you did an online consultation...
 - What did you want to happen? – What kind of response were you hoping for?
 - [E.g. Face to face appointment, telephone call, email or text from the practice?]
 - What did happen? – How did the consultation take place?
 - Were you happy or unhappy with that?
 - Did you speak to someone? - Who? - Were they the person you wanted to speak to?
 - Were you involved in making decisions about your care?
 - To what extent did you want to be involved in this?
 - How was the outcome/decision communicated to you?
 - How pleased, or not, were you with the outcome/decision?
 - What is your perception of the quality of care you received?

- On that occasion, were your expectations met?
10. In general, does the system deliver the benefits you were expecting?
- [Refer to what they hoped to get out of it.]
11. How do you think your use of the system has affected the way you communicate with your GP/nurse when you have an issue?
- Is it a useful and trustworthy way of communicating with you GP?
 - Was that expected or unexpected?
12. What impact has using online consultations had on your relationship with your GP/nurse
- Was that expected or unexpected?

Online consultation systems are promoted as a way to direct people to alternative sources of advice, such as online resources or pharmacists for example, as a way to make getting advice more efficient, by not having to wait for a face-to-face appointment, and also as a way to improve your access to GPs by giving you a different way in besides phoning up, for example...

13. ...Beyond this, has it been useful in other ways you didn't expect? – What ways?
- [E.g. convenient to complete, quicker response, reducing unnecessary travel.]
 - Can you tell me more about that?
 - How did you feel about that?
14. Has it been unhelpful in ways you didn't expect? – What ways?
- Can you tell me more about that?
 - How did you feel about that?
15. What could be done to improve the system?

PATIENT ONLINE ACCESS TO THEIR MEDICAL RECORDS

Intended Consequences

- **Allow patients to have greater control and more information about their own health.**
- **Help patients play a central role in decisions about their medical care. E.g. checking or revisiting details of previous consultations.**
- **Improve efficiency of care and freeing up GP time. E.g. not needing to contact practices to get copies of your immunisation history.**

16. Which of the practices' online services do you use?

- E.g. 'Patient Access' which may allow you do things like to book appointments, view your medications and allergies, and view your medical record.

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- [Need to focus the participant that it is access to their medical records that we are interested in]

16. Do you have access to your medical records online?

- Have you looked at them?
- What information can you view?

17. Why did you decide to access your medical records online?

- Why did you sign up for access?
- What were you hoping to get out of using it?
- What were you hoping to get out of viewing your medical record online?

18. What did you hope the benefits to you would be?

- [E.g. access information quickly/without contacting practice, check information]

19. What was your experience of using the system? - How well does it work?

- How often do you view your record online?
- What sorts of things prompt you to review them?
- How happy are you with the amount of information that's available?
- How far back in time does the information go?
- How easy or difficult is it to understand? – Why? [terminology, shorthand]

20. How, if at all, does it affect how you manage your health?

- Was this an effect that was expected or unexpected?

21. How do you think being able to view your medical record has affected the way you talk about your health to your GP/nurse?

- Was this an effect that was expected or unexpected?

22. What impact has it had on your relationship with your GP/nurse?

- Was this an effect that was expected or unexpected?

Giving people online access to their medical records is promoted as a way to allow patients to have greater control and more information about their own health, help them play a central role in decisions about their medical care, and also free up time on the practice-side, by allowing people to get their own copies of immunisation history for example...

23. ...Beyond this, has it been useful in ways you didn't expect? – what ways?

- E.g. correcting errors, delegated access to others

24. Has it been unhelpful in ways you didn't expect? – what ways?

- Do you have any concerns about your medical record being available online?
 - E.g. Privacy/security/confidentiality
- How might those negative consequences be dealt with?

25. Does anyone else in your household have access to your medical records?

- How do you share access?
- Why did you decided to share access?
- How has it been helpful? [in expected/unexpected ways]
- How has it been unhelpful? [in expected/unexpected ways]

26. What could be done to improve the system?

- What could be done to make the information more useful to you?
- What extra information would be most useful?

SMARTPHONE APPS FOR MANAGING LONG-TERM CONDITIONS

Intended Consequences

- **Identify risks or facilitate health**
- **Self-tracking or monitoring different aspects of your health. E.g. helping people with diabetes to monitor their blood sugar levels more closely.**
- **Help people play a central role in managing their health. E.g. giving people with anxiety or depression tools they can use themselves outside of a consultation.**
- **Improve efficiency of care and free up GP time.**

27. Do you use any health-related apps? - What apps?

- What medical conditions do you use them for?

28. Thinking about the app for [long term condition(s)]...

- What does it do? How does it work?
- How long have you used it for?
- Do you have to pay for it?

29. Why did you decide to use the app?

- How did you find about it? [self discover / GP recommended]
- What range of apps were available to choose from?
- What made you decide to choose the one you did?
- Have you ever brought it up in discussions with your GP/Nurse? – why/why not

30. Before you used it for the first time, what were you hoping to get out of the app?

- Do you have any thoughts about the security and confidentiality of it?
- Do you have any thoughts about the trustworthiness or quality of it?

31. What did you hope the benefits for you would be?

32. Can you tell me what your experience of using the app has been like?

- Have those benefits materialised?

33. How do you think your use of the app has affected the way you communicate issues to your GP/nurse, even if you don't show them the app?

- [E.g. More confidence about own history / better understanding of condition?]
- Was this an effect that was expected or unexpected?

34. Has this impacted on your relationship with your GP/nurse?

- [E.g. More or Less contact, more autonomy, greater responsibility for managing your condition, raised anxiety about your condition?]
- Was this an effect that was expected or unexpected?

The use of smartphone apps to manage long term conditions is promoted as a way to allow people to better monitor different aspects of their health, help people play a central role in managing their health, Improve efficiency of care and free up GP time...

35. ...Beyond this, have there been other consequences from using it that you weren't expecting? – such as?

- [E.g. Surprises or significant events / learning new things about yourself or your condition / changed your attitude towards or management of your condition?]

36. Have you changed the way you use the app at all? – in what ways?

- Is there anything you'd change about the app, to make it more useful?
 - To you
 - To your GP/nurse?

CLOSE

37. Patient demographics: age; gender; ethnicity

Do you have anything to add before we finish the interview?

Ask them

- **For their address, so we can send them a £20 shopping voucher as thanks for participating.**
- **Whether they want to receive a copy of the study report when complete.**