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CLINICAL RESEARCH NETWORK.  
NORTH EAST AND NORTH CUMBRIA.

# The Connected Patient Project: Report

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**12th July 2019**

## Summary

The NHS pledges to allow every patient access to research. There are known benefits to engaging in research, despite this it is reported that only 14% of patients are participating. To help address this, research capacity and capability is being built in primary care. It is hoped this will aid the shift of research from a secondary care to a primary care setting. Additionally, there is a move to utilise digital communication mediums across the health sector. This links to the vision that each patient will have a single dynamic medical and social care record which they can access. As part of their access the patient will set their own data sharing and communications preferences.

The Connected Patient Project was set in a General Practice and explored the acceptability and feasibility of a novel recruitment strategy. Its ambition was to build a local registry of patients who had indicated their permission (yes or no) to be contacted directly by researchers with information about relevant research projects. To facilitate this, personal details would be shared with the specific organisation. The three organisations put forward were: NHS, Universities, and Commercial Companies.

Added to this the project also asked the patients to indicate their preferred mode of contact from the practice to themselves. This was to gauge the willingness of patients to move towards digital communication and explore the most acceptable method.

The aim and objectives of the Connect Patient Project were:

Aim:

To evaluate a service improvement project for acceptability and feasibility from the viewpoint of patients and practice staff.

Objectives:

1. To explore the influences on patient choices and identify if there are any correlations between patient preferences on data sharing, preferred mode of contact, age range, gender and presence or not of a long-term condition.
2. To assess the impact of carrying out the service improvement project from the view point of practice employees.
3. To explore levels of trust patients have in different organisations: NHS trusts, Universities, and Commercial Companies.

4. To describe the elements patients take into account when making decisions about potentially sharing personal information.

The project was operationalised via a two-stage process. Work Package 1 (WP1) was a Service Improvement Project (SIP) conducted by a postal survey questionnaire. The questionnaire was sent to all the patients who fell within the inclusion and exclusion criteria (4678).

Work Package 2 (WP2) was a mixed methods research study to assess the acceptability and feasibility of WP1. This was completed by using descriptive statistics and by conducting interviews with both patients and staff.

The WP1 survey had a response rate of 24%. Older, female patients were more likely to respond. 58% of the total 60+ age group responded. 4% of the 18-29yrs. age group responded. SMS was the most popular mode of contact across all age groups with the exception of the 70+ age group, where letter was preferred. Permission to contact by at least one of the three organisations was given by 61% of the responders. The single most popular response was NNN, where permission was denied to all three organisations. This was followed by YYY, which gave permission to all three organisations. Women were more likely to respond yes than men, with the exception of the 70+ age group where more women said NNN, than men. The presence or not of a long-term condition did not affect the permissions responses. However, reflecting the demographic profile of the responders, they were more likely to have a long-term condition.

Interview data revealed that the patient interviewees had volunteered for altruistic and reciprocal reasons. When making decisions regarding sharing personal information, trust is very important. Commercial research organisations are not trusted, despite the knowledge of partnership working in the NHS. Digital contact is seen as progress but other means of contact should not be removed entirely.

Staff interviewees stated that the impact on the practice was far less than expected. The processes required to complete the project took longer than initially thought. The wording of the original information may have been off putting and could be a reason for the non-response. The gain for the practice was seen as a mandate to expand the use of SMS as a contact method. However, this is currently limited by the functionality of the systems in use. Email contact requires further detailed processes.

The SIP was acceptable and feasible for patients and the practice staff. However, the response rate of 24% would suggest it is not a feasible way to build a registry of patients. Whether it affects recruitment has not yet been established.

Recommendations from the project are:

- In any further iteration, strategies to reduce non-response should be engaged with.
- Splitting the component parts of the project into individual studies may aid understanding and engagement by the eligible population.
- Further work is required to explore the scope and acceptability of SMS and email contact.
- Additional work is required to explore the granularity of permissions and the rationale for choice.
- Overt commercialisation of the research process may hinder recruitment.
- Studies in primary care should be targeted at health promotion and chronic disease.
- Further work is required at a regional and national level to better articulate the role of commercial companies in NHS research.
- Further explore the value and test the outputs from this study by using the practice to approach patients about relevant research. This would facilitate an assessment of the willingness to engage with researchers, when compared with routine response rates from general mail-outs in primary care.

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## Introduction

The National Health Service (NHS) pledges to give every patient the opportunity to take part in research studies [1]. Known benefits can be gained from engaging in research [2]. Despite this a survey conducted by the National Institute for Health Research (NIHR) suggested only 14 percent of patients were engaged in research [3]. In addition, only 32% of General Practices in England are currently research active [4].

The place, content and context of health research is changing. There is a shift from secondary care to primary care to enable research to take place in the populations where disease is at its highest [5]. Integrated Care Systems offer an opportunity to embed research as a part of primary care. To facilitate this, research capacity and capability is being built in primary care [6].

The Connected Patient Project (CPP) explores how acceptable and feasible it is for a practice population to indicate their data sharing preferences to enable researchers to contact them directly. The Service Improvement Project (SIP) investigates a novel recruitment strategy directed at building a viable practice registry of patients who have given permission for the practice to share their personal contact information. From this local registry the aim is to progress to a regional and then national registry to better facilitate recruitment to research projects set in primary care. The project is complementary to and forms part of the ongoing work of Connected Health Cities which is looking at online and offline tools for the general public to set their own data sharing preferences [7]. This work is linked to the Digital Transformation Programme within the NHS and is a combination of views from Personal Health Care 2020 [8], Five Year Forward View [9], the Wachter Review [10] and the NHS Long-term Plan [11] being overseen by NHSX [12].

There is a known reserve from the public regarding data sharing [13] [14] [15]. Headline stories regarding data breaches, use of personal data and cyber-attacks highlight the need for the public to be fully informed about why and how their identifiable information is used. Reticence to share coalesces around issues regarding confidentiality, abuse of information, potential harm arising from the leaking of information and the competence of organisations to keep it safe [13] [14] [16]. It is hoped this project will go some way to improving individual patients understanding of how their health information is already used and how secure data sharing could lead to improved access to health-related research [17] [18] [19]. In addition, those working on the Connected Health Cities [20] projects can utilise the findings to tailor their approaches. Their aim, in phase 2 of their work, is to integrate health and social care records, so that individuals can interact with health and social care services via a website or app. This will allow them to indicate their own preferred communication mode and data sharing preferences [21]. This will lead to people being able to view correspondence

and key medical information. A consequence of this centralisation and streamlining will be improved access to large data sets for researchers.

Raising awareness of digital connectivity in primary care and facilitating patient engagement with enhanced digital mediums moves towards a time when patients will have access to and control over their own health information. Enabling people to control their own data sharing preference goes some way to building confidence in organisations to use personal data in a secure way to benefit individuals and wider populations.

Research rich environments deliver better care [22]. New and innovative ways are required to enhance the uptake of research in primary care. One way of doing this is to improve the ways information technology systems can be harnessed to make processes more efficient and manageable.

In addition to investigating patients' willingness to share personal data, this project also explores digital connectivity. In 2013 the then Health Secretary challenged the NHS to be paperless by 2018 [23]. Whilst this has been revised it still remains a focus in the recent NHS Long-term Plan [11]. Innovations such as The NHS App [24] [25], aim to provide secure access to services and information. It will be an adjunct to GP online services, interfacing with both Total Patient Package (TPP) and Egton Medical Information Systems (EMIS) to allow appointment booking and prescription ordering. Added to this, projects are taking place across the NHS acute services to allow digital correspondence to be sent to patients [26] [27]. This is the start of processes to utilise more economical and environmentally friendly methods of contacting patients. It has been reported that the NHS spends £100 million a year posting out appointment letters [28]. With this in mind, a strand of this work looked at patients' preferred mode of contact and their rationale for that choice.

## **Location, Sponsorship and Ethical Review**

The project was carried out in a General Practice sited in the North East of England. It was funded by the NIHR (National Institute for Health Research) Clinical Research Network (CRN) North East and North Cumbria (NENC) and Connected Health Cities. It was sponsored by The Newcastle upon Tyne Hospitals NHS Foundation Trust. Ethical approval was gained from both the sponsoring trust and The Health Research Authority East Midlands–Derby committee.

## **Setting**

The village where the practice is situated is on the outskirts of a previously industrial town. In 1980 its heavy industry closed and, with the associated decline in the mining industry, it resulted in almost total male unemployment. The area has 20% fewer higher and intermediate managerial,



administrative and professional households than the national average. The rate of unemployment remains higher than the county and national average. The rates of those claiming any benefit are 25% higher than the national average, suggesting under-employment and low salaries [29]. The area was noted in 2015 to have worsening levels of relative deprivation [30]. Geographically the village is situated within 30 minutes' drive of major cities and within 15 minutes of an Area of Outstanding Natural Beauty.

## **Funding**

Funding was utilised by employing a project coordinator for 18 months at 0.4 of full time equivalent. This role encompassed protocol production, ethical approvals, project management, data collection, data analysis and report production. In addition, the practice was funded for their use of docmail®, the setting up of a prepaid postal returns licence via Royal Mail and administration time to backfill a Band 5 post for 12 months at 0.5 of full time equivalent. The project was completed within budget. There was a 6-month extension to the end date due to the time required to gain ethical approvals.

## **Aims and objectives:**

**Aim:** to evaluate a service improvement project for acceptability and feasibility from the viewpoint of patients and practice staff.

**Objectives:**

- 1.To explore the influences on patient choices and identify if there are any correlations between patient preferences on data sharing, preferred mode of contact, age range, gender and presence or not of a long-term condition.
- 2.To assess the impact of carrying out the service improvement project from the view point of practice employees.
- 3.To explore levels of trust patients have in different organisations: NHS trusts, Universities, and Commercial Companies.
- 4.To describe the elements patients take into account when making decisions about potentially sharing personal information.

## **Methodology**

A mixed methods project was designed incorporating two work packages. Work Package 1 (WP1) was conducted by the General Practice as a Service Improvement Project. Work Package 2 (WP2)

was conducted by a researcher employed by CRN NENC. It described the findings from WP1, explored the reasoning for the decisions made by patients in WP1, and examined the feasibility and acceptability of extending WP1 to other sites.

WP1 was operationalised via a survey questionnaire (Appendix I) and WP2 via descriptive statistics, an activity analysis tool (Appendix II) and semi-structured interviews with practice staff and patients. The survey was mailed directly from the practice to patients using docmails® secure application programming interface.

## Sample

### Inclusion criteria:

All patients registered with the practice who are 18 years or over at the time of contact.

All staff working within the practice.

### Exclusion criteria:

Patients under the age of 18 years at the time of contact.

Patients currently on the palliative care register.

Patients unable to give an informed consent (interviews).

Total sample was 4678 patients.

Total sample staff 15.

Target number of responders from the survey was 1000.

Anticipated number of interviews (staff and patients) was 30. Patients were purposively sampled with the aim of reflecting a range of responses across the demographic profile. Staff were sampled according to their involvement in the project. All interview participants were volunteers.

## Data Collection

### Work Package 1

Patients were asked, via a survey questionnaire (Appendix I), to indicate their preferred way for the practice to contact them about routine non-urgent matters. They were given the options of email, text or letter.

Secondly, they were invited to indicate (Yes or No) if they gave the practice permission to share their personal information with researchers from three different organisations. The organisations were: NHS, Universities and Commercial companies.

The information contained with the survey informed the patient that the organisation may go on to contact them to inform patients of relevant research only. The patient could then, if they wished, express an interest in taking part in the research. Further information was given about what currently happens with personal data within the practice. Additional information was signposted should it be required. The survey went on to explain what would happen to the responses the patient gave and how these would be used in WP2. Responders were informed that by returning the survey they were giving their implied consent for the researcher to access limited demographic and health information. They could indicate that they did not want the researcher to access their information. The package sent to the patient included a pre-paid postal return envelope. Patients were informed they could return the survey in person, via the pre-paid envelope or, if they had one, via their online account. QR codes were added to the information which linked to the online account login page and the additional information. Advice was also given to allow patients to set-up an online account if they wished to.

## **Work Package 2**

The quantitative statistical information gained from the survey was correlated in Excel and added to the practice clinical system (TPP) to allow cross referencing. The practice supplied aggregated anonymised data for those who declined the researcher access. Qualitative data was collected via semi-structured interviews, using topic guides (Appendix III), from patient and staff participants who had given a written informed consent. Patient interviews explored the reasoning behind the choices made and thoughts behind the practicality of the project. Staff interviews examined the impact of WP1 to explore the feasibility of WP1 from the practices perspective and also used an activity analysis tool.

## **Data analysis**

### **Quantitative**

Anonymised descriptive statistics in the form of percentages were used to illustrate the demographic profile of the whole sample group. Response rates were calculated and cross-referenced with the choices made, age group, sex and presence or not of a long-term condition. Preferred mode of contact was recorded in a spreadsheet and added to the clinical record via the administration templates. Digital connectivity was analysed by noting the response rate across

differing modalities and any changes in the number of online accounts, mobile phone numbers and email addresses held.

Data sharing preferences were recorded on an Excel spreadsheet and also within the individual's clinical record. There were eight possible combinations of responses (Table 1).

	NHS Researchers	University Researchers	Commercial Researchers
Possible responses	Yes	Yes	Yes
	Yes	Yes	No
	Yes	No	No
	Yes	No	Yes
	No	Yes	Yes
	No	Yes	No
	No	No	Yes
	No	No	No

Table 1: Possible combinations of data sharing preference responses.

## Qualitative

Digital voice recordings were transcribed by the researcher. All information was anonymised and participants given an identifier. Transcripts were then re-read and thematically analysed using the six-step approach [31] [32]. The findings were triangulated with the statistical responses and data analysis and discussed within the core research team.

The above methodology allowed the aim and objectives of the project to be achieved.

## Findings

### Response rate to survey questionnaire

Of the total practice population of 5946 patients, 4678 were eligible for the SIP. All of these patients received one copy of the survey via letter between December 2018 and the end of March 2019. The participant list was sorted via NHS number and send out in batches of between 350 and 750. Survey

activity was suspended over the Christmas and New Year period. Below is the age/sex profile of the eligible population.

Age	Total	Male	Female
18-29	808 (17%)	391 (48%)	417 (52%)
30-39	836 (18%)	396 (47%)	440 (53%)
40-49	784 (17%)	397 (51%)	387 (49%)
50-59	863 (18%)	423 (49%)	440 (51%)
60-69	669 (14%)	307 (46%)	362 (54%)
70 plus	718 (15%)	325 (45%)	393 (55%)
	<b>4678</b>	<b>2239 (48%)</b>	<b>2439 (52%)</b>

Table 2 Demographic profile of the eligible group.

The overall response rate was 24% (n=1148)

34% (n=392) of those who responded declined access to their anonymous data by the researcher based in the practice. Aggregated data on these participants was supplied by the practice and is included in the figures below unless stated.

Below is the age/sex profile of the survey responders who gave permission for the researcher to access their anonymised data.

Age group	Total number of responders who allowed the researcher to access their anonymised data = 756	Male	Female
18-29 yrs.	36 = 4%	15 = 42%	21 = 58%
30-39 yrs.	63 = 8%	18 = 29%	45 = 71%
40-49 yrs.	87 = 11%	43 = 49%	44 = 51%
50-59 yrs.	146 = 17%	58 = 40%	88 = 60%
60-69 yrs.	203 = 30%	90 = 44%	113 = 56%
70 + yrs.	221 = 31%	107 = 48%	114 = 52%
		<b>331 = 44%</b>	<b>425 = 56%</b>

Table 3: Demographic profile of the responders who allowed the researcher access.

Below is the age/sex profile of those who declined access to the researcher (data supplied by the practice).

Age group	Total number of responders who declined the researcher to access their anonymised data = 392	Male	Female
18-29 yrs.	15 = 4%	6 = 40%	9 = 60%
30-39 yrs.	26 = 7%	10 = 38%	16 = 62%
40-49 yrs.	41 = 10%	20 = 49%	21 = 51%
50-59 yrs.	72 = 18%	34 = 47%	38 = 53%
60-69 yrs.	98 = 25%	40 = 40%	58 = 60%
70 + yrs.	140 = 36%	61 = 44%	79 = 56%
		<b>171 = 44%</b>	<b>221 = 56%</b>

Table 4: Demographic profile of the responders who declined the researcher access.

### Responders by age and sex profile

Responders across all age groups were more likely to be female. The female response rate was 26%, the male was 22%; this difference is highly statistically significant ( $p < 0.01$ ). Increasing age was correlated with response rate. 58% ( $n = 662$ ) of the eligible over 60 yrs. of age group responded, conversely 4% ( $N = 51$ ) of the eligible 18-29 yrs. age group responded. This age difference in response rate is also highly statistically significant. The demographic profile of the participants whose data was supplied by the practice broadly matches those who allowed the researcher to access their anonymised data.

### Route of response

28% ( $n = 1309$ ) of the eligible population were recorded as having an online account. Of those 4% ( $n = 47$ ) responded via this route. Of these, 40% ( $n = 16$ ) were in the 60-69 yrs. age bracket. Caution needs to be taken when interpreting these results as it is not known how many of those who have registered for an online account are active users. Interview data showed that of six interviewees who had online accounts, two did not use the account.

It is possible to estimate the number who returned their survey in the pre-paid envelope by using the total amount paid to the Royal Mail, where each return costs 40 pence. Using this, the estimated number who returned by pre-paid post is 912, 79% of the total response. It is fair to assume the remaining 189 responders returned the survey by hand.

In the 12 weeks prior to the survey period, there were 55 requests to set up online accounts. During the survey period of 18 weeks there were 85 requests to set up an online account.

## Findings: mode of contact

### Contact preferences

Baseline data showed that the practice held a mobile phone number for 3617 (77%) of the eligible population. There were only 15 (0.3%) of the eligible population who had an email address where permission had been gained to use it for contact. For permission to be gained, the patient is required to validate their email address with the practice. This is done by responding to an email which is automatically generated by TPP once an email address is entered and selected as the preferred mode of contact. Of those 15 email addresses, three appeared to be multiple person use, e.g. thesmiths@ and two were work email addresses (.ac.uk or .gov.uk). Anecdotally, during the data entry process those who entered data remarked on the number of email addresses that required updating. There appeared to be a large number of email addresses held that were out of date and had not been either selected as the preferred mode of contact or validated by the patient. The use of email as a contact method will be discussed further in the report.

Data extracted after the survey revealed that there had been a modest increase in mobile phone numbers held, to 3716 (an increase of 2%). Verified email accounts had increased from 15 to 185, which is 3% of the eligible population.

As expected, contact method was correlated to age. Whilst SMS messaging was the preferred overall mode to contact, there was a significant difference in the 70+ age band where 54% (n=225) preferred letter contact. Of interest is that, of those who declined the researcher access, 49% (n=194) preferred letter contact and 9% (n=36) indicated no choice.

Practice Contact preferences by age							
Age group	18-29	30-39	40-49	50-59	60-69	70+	Totals
Email	5 (3%)	16 (9%)	18 (11%)	39 (23%)	51 (30%)	42 (25%)	<b>171 = 16%</b>
SMS	35 (8%)	38 (8%)	66 (15%)	122 (27%)	125 (27%)	69 (15%)	<b>455 = 44%</b>
Letter	14 (3%)	11 (3%)	35 (8%)	40 (10%)	91 (22%)	225 (54%)	<b>416 = 40%</b>
	<b>54 (5%)</b>	<b>65 (6%)</b>	<b>119 (11%)</b>	<b>201 (19%)</b>	<b>267 (26%)</b>	<b>336 (32%)</b>	<b>1042</b>
Number who put more than 1 method				60 (5%)	These are not included in the above figures.		
Number with no choice				46 (4%)			

Table 5: Contact preferences by age.

## Findings: data sharing preferences

### Permissions preferences

61% (n=703) of the total number of those who responded gave permission to be contacted by at least one of the three organisations. This equates to 15% of the eligible population. The most popular organisation was the NHS, and the most common choice was NNN, declining permission to all organisations. 82% (n=323) of those who declined the researcher access also declined permission to contact to all organisations. The table below contains a further breakdown of the permissions.

NHS	University	Commercial	Total Number of responses	Proportion of responses with permission for researcher to see (756)	Proportion of responses who declined researcher access (392) (data supplied by practice)	Proportion of total number of responses (1148)	Proportion of total sample size (4678)
Yes	Yes	Yes	378	346 = 46%	32 = 8%	33%	8%
Yes	Yes	No	244	224 = 30%	20 = 5%	21%	5%



Yes	No	No	75	60 = 8%	15 = 4%	7%	2%
Yes	No	Yes	3	2 = 0.30%	1 = 0.2%	0.20%	0.06%
No	Yes	Yes	0	0			
No	Yes	No	3	2 = 0.30%	1 = 0.2%	0.20%	0.06%
No	No	Yes	0	0			
No	No	No	445	122 = 16%	323 = 82%	39%	10%
			<b>1148</b>				

Table 6: Permissions preferences.

Table 7 shows that females on the whole were more likely to say yes to one or more of the organisations. In the 70+ yrs. age group men tended to say YYY and women NNN. In the 18-39 yrs. and the 50-69yrs groups females were more likely to say yes to data sharing with at least one of the organisations. There was no significant sex difference in the 40-49yrs age group. These differences in permissions choices were too small to reach statistical significance.

NHS	University	Commercial	Number of patients	18-29 yrs.	30-39 yrs.	40-49 yrs.	50-59 yrs.	60-69 yrs.	70+ yrs.	Male	Female
Yes	Yes	Yes	378	18 = 5% (5m 13f)	25 = 7% (9m 16f)	43 = 11% (23m 20f)	71 = 19% (31m 40f)	96 = 25% (34m 62f)	125 = 33% (65m 60f)	167 44%	211 56%
Yes	Yes	No	244	8 = 3% (4m 4f)	23 = 9% (5m 18f)	25 = 10% (10m 15f)	50 = 20% (13m 37f)	71 = 29% (32m 39f)	67 = 27% (29m 38f)	93 38%	151 62%
Yes	No	No	75	3 = 4% (0m 3f)	6 = 8% (2m 4f)	5 = 7% (3m 2f)	18 = 24% (8m 10f)	16 = 21% (9m 7f)	27 = 36% (12m 15f)	34 45%	41 55%

Yes	No	Yes	3						3 = 100% (3m 0f)	3	
No	Yes	Yes	0								
No	Yes	No	3			1 = 33% (1m 0f)		1 = 33% (0m 1f)	1 = 33% (1m 0f)	2	1
No	No	Yes	0								
No	No	No	445	22 = 5% (12m 10f)	35 = 8% (12m 23f)	54 = 12% (26m 28f)	79 = 18% (40m 39f)	117 = 26% (55m 62f)	138 = 31% (58m 80f)	203	242
			<b>1148</b>	<b>51</b> <b>(4%)</b>	<b>89</b> <b>(8%)</b>	<b>128</b> <b>(11%)</b>	<b>218</b> <b>(19%)</b>	<b>301</b> <b>(26%)</b>	<b>361</b> <b>(34%)</b>	<b>502</b> <b>(44%)</b>	<b>646</b> <b>(56%)</b>

Table 7: Permissions by age and sex.

### Permissions preferences and long-term conditions (LTC).

41% of the eligible cohort had a LTC. 60% (n=692) of all responders had a long-term condition. It appears from Table 8 that having a long-term condition does not appear to impact on the permissions choices made.

	Those with a long-term condition	Those without a long-term condition
Gives permission to all three organisations	33%	31%
Refuses permission to all three organisations	38%	39%
Gives permission for NHS researchers to contact only	7%	7%

Table 8: Permissions and LTC.

## Findings: patient interviews

### Description of interview participants (patients)

The information sent out with the SIP contained an open invitation to contact the interviewer to discuss the project. Of the 4678 surveys sent, two interviewees made contact via this route. In addition, 85 personal invitations were sent out by the researcher working in the practice. These included a range of ages and permissions choices from those who had given authorisation for NHS researchers to contact them. From those 85 a further seven interviewees came forward. The practice sent 30 letters to NNN responders: no-one came forward from this route. A total of nine patient interviews were completed. Three had responded to the permission choices as YYY, two YYN and four YNN. Six preferred contact by email, two by text and one by letter. The average length of interviews was 26 mins. (19mins-40mins). All but two had difficulty recalling the choices they had

made and four of the nine inaccurately recalled the choices when their interview responses were cross-referenced with their survey responses.

The demographic profile of interviewees was 1 x 40-49yrs, 2x 50-59yrs, 4x 60-69yrs, 2x 70yrs plus. Six were female and three were male. Seven participants had a long-term condition, two did not. Four participants had online accounts and were active uses, two had an account but did not use it and three had no account. Two responded to the survey via their online account. No interviewee had sought out further information or advice prior to making their choices and returning their survey form.

All participants stated they had no or very limited use of social media (Facebook, WhatsApp, Instagram, Twitter, Pinterest). All the participants had access to and used the internet via electronic devices. While all had mobile phones, some only used them for emergencies, preferring to use tablets or computers (desk top/lap top) for internet access.

In addition, eight of the interview participants were either actively involved in research (The Million Women Study, UK Biobank Study), or had previously been personally involved in research, as a participant or staff.

### **Thematic findings (patients)**

The narrative text supporting the formation of the themes is contained in Appendix IV. Four themes were identified via the analysis process. These were:

Understanding of the project and its associated correspondence

Motivations

Trust and mistrust

Progress

#### ***Understanding:***

The patients thought the project was broadly about communication between themselves, the practice and the wider NHS. The permission to contact for research purposes was mentioned by two people prior to being prompted by the interviewer. All participants felt the information sent out in the SIP could have been condensed. However, they felt that receiving the survey by post and directly from the practice engaged their interest and added to the bona-fide nature of the project.

Data sharing and research were regarded as necessary. There was an understanding that decisions about health care needed to be made from an evidence base. On the whole interviewees had

conflated the information about the routine extraction of patient data from notes for research, public health, service evaluation and commissioning, with the primary research aspect where they were being asked to give permission for researchers to contact them directly.

When asked what research they felt they may be involved in, most participants linked that to their own situation and health status. The most common things were personal illnesses, potential future illnesses, lifestyle and age-specific health promotion. Clinical research (drug studies) was discussed twice. Once was to state the participant would not like to do drug related research and the second was linked to a specific disease and a hope for future treatment options. No particular health areas were seen as off-limits, although there was an awareness that for some there could be 'sensitive' or 'embarrassing' areas. There was also the view that information should be used to track and improve non-attendance rates to GP appointments. When questioned about their understanding that pseudo-anonymised data was routinely utilised, most had a pragmatic view about the necessity of that and while they may not have thought about it prior to receiving the information it seemed a reasonable thing to do. This was caveated by the notions of confidentiality and anonymity.

#### *Motivations:*

All expressed altruistic motives and reciprocity. These were linked to the reasons for returning the survey, taking part in the research interview and the permissions given for researchers to contact. The participants engaged through loyalty and support of their general practice and the wider NHS. Some expressed views of empowerment. They saw the returning of the survey and the taking part in the interview as the practice listening to them and their concerns and views being taken into consideration. This was then linked to wider support and improvement of the NHS. A strong anti-privatisation rhetoric was expressed by some, with a hagiographic element attached to the NHS as an institution.

The 'giving something back' was associated with a health cue to action. The participants had either long-term or chronic conditions, had been lifelong users of the NHS, and were prompted by notions of being able to improve their own health or gain improved health surveillance by taking part in research. Aging was also seen as a cue, it being associated with a higher risk of illness. There was a perception that taking part in research may somehow lead to better surveillance and potentially the diagnosis and treatment of conditions participants already had or may have in the future.

Preferred contact choice of SMS or email was motivated by convenience, previous use and the knowledge these were cheaper options for the NHS/GP surgery.

### ***Trust and mistrust:***

Questioning participants about the reasons for the permissions choices elicited views on trust and mistrust.

The NHS was a trusted brand; all previous data breaches were silenced. Where it was perceived mistakes had happened, these were rationalised as rare and ‘only human’. Universities and academics were also trusted but with less overt effusiveness than the NHS. The NHS and University setting were perceived as not for profit which increased their trustworthiness. Trust and mistrust on the whole were thought of as a ‘gut reaction’.

For research and researchers to be trusted, projects needed to have clear purposes and outcomes for the good of the wider society. They also need to be unbiased, transparent and not pushing specific agendas. Participants who had knowledge of the University sector felt they might be drawn into ‘student’ projects which may have limited impact and outcome. Trust was also linked to anonymisation processes, confidentiality and the ability to change your mind and therefore your personal permissions choices. Permissions and choices need to be responsive and dynamic to the individuals’ lives and potential changes in circumstances.

In comparison the word ‘commercial’ had a significant amount of mistrust attached to it. Even in situations where interviewees understood the partnership working of commercial and NHS research, their gut feelings were to distrust the commercial element. The phrases associated with commercial research were: ‘*money making*’, ‘*selling data on*’, ‘*lack of impartiality*’, ‘*less honourable*’, ‘*promotional material*’ and ‘*not interested in people*’.

Social media was wholly mistrusted, as were some digital contact mediums. Participants talked about instances of covert removal of personal data, ID fraud, card scamming, phishing emails and scam emails/SMS. All took steps to limit the sharing of their personal information. One participant spoke about feelings of control and surveillance from digital mediums and feeling isolated from social and family groups by their own reluctance to engage with social media. In contrast it was suggested that the NHS operates up to date security systems and that data has not been lost or misused by this organisation.

### ***Progress:***

While participants were in favour of progress and a general movement towards SMS and digital contact all felt letters should still be utilised. Increased utilisation of smart phones was linked by some to difficulties in reading large amounts of text on a small screen. SMS appointment reminders

were supported fully. In addition, there was a hope that the 'human face' was not replaced by further digital interface. Face to face contacts with GPs and reception staff were welcomed.

One participant expressed the view that the digital online account could have more functionality. It was thought it could be used to signpost health promotion, screening or research opportunities.

To summarise, the patient interview participants reflected the demographic profile of the survey respondents. All had given permission to share their personal contact details with at least one of the three organisations. They were not frequent social media users but did access the internet. All expressed notions of reciprocity and altruism. When making decisions regarding sharing personal information, trust is very important. Commercial research organisations are not trusted, despite the knowledge of partnership working in the NHS. Digital contact is seen as progress but other means of contact should not be removed entirely.

### **Findings: activity analysis and staff interviews.**

As part of the feasibility evaluation it was planned to interview all staff who had a role in the SIP. In addition, an activity analysis tool was utilised by the practice reception staff to capture the time spent dealing with direct questions or comments regarding the SIP from patients.

The project had minimal impact on the practice reception staff. Only one person directly spoke to the staff regarding the project. That interaction was a request for the researcher to contact them directly. The researcher working in the practice dealt with the survey responses as they were returned. Data entry of the responses was completed in one-off additional sessions that were financed from the funding secured by the practice.

The two members of staff who were involved in the SIP were interviewed. One was interviewed 3 times (LG001S) the other (LG002S) twice. LG001S was involved in the collection of baseline and post-survey statistics, uploading data to docmail®, and the setting up of the Royal Mail postal account and pre-paid returns licence. LG002S updated the clinical system with specific read codes for the survey findings, added the survey to the online portal and designed and ran the searches for the post-survey findings.

Initial interviews were conducted before the first surveys had been sent out. The second interview with LG001S was conducted approximately 1 month into the survey period. The final interviews with both participants were conducted once data collection had been completed.

### **Thematic findings (staff)**

Themes from the interviews were:

Understanding of the research project

Processes undertaken

Drivers and inhibitors

Findings and outcomes.

### *Understanding of the project*

From the practice's perspective the project was seen as a way of recognising the volume and diversity of the information primary care holds. In addition, it was seen as maximising the routes of communication and as a way of ensuring the patients were informed and comfortable with how their data was being used, and could be used in the future. Primary care was perceived as an untapped resource for the research community, in respect of both information and individual participants.

Discussions in the initial interviews covered the content of the SIP information (Work Package 1) and the subsequent research project (Work Package 2). It centred on the wording of the material which described the routine use of data and the requirement for implied consent. It was felt it was imperative to get this right to maximise the response rate. Later interviews concurred with the patient interviewee views regarding the length of the survey information and suggested it had become 'cold' and therefore off-putting. It was also suggested that the legislation, the data flow and signposting to further information was difficult to communicate in a way that ensured understanding.

### *Processes undertaken*

#### *Workload*

Initial interviews explored the potential for the project to cause an increase in workload. It was felt this may come directly from patients in the form of questions regarding the routine use of general practice data. A range of strategies were discussed which included a frequently asked questions document, a presentation regarding the research and regular update meetings. All these were instigated, however as discussed previously there was minimal impact from this route on the practice staff.

Prior to sending out the SIP the main processes involved the updating of the clinical system with specific read codes and putting the survey questionnaire onto the online portal. Additional processes included: collecting baseline data, identifying the eligible cohort, cleaning the contact information to allow uploads to docmail®, and the setting up of a Royal Mail pre-paid account. In these initial stages

it was the address format in docmail® that was seen as the biggest *'hurdle'*. However, once the format had been corrected, global changes were made to the cohort's information so that subsequent uploads were quick and issue free.

### Research process

Toward the end of the project an issue was identified regarding the updating of the eligible cohort dataset. Three instances came to light where an individual's details had changed in the time between compiling the cohort dataset and uploading the information to the docmail® system. It was noted that there was a need for the cohort dataset to be dynamic and constantly updated prior to each mail-out, or for the mail-out to be completed in one batch ensuring the eligible cohort details remained accurate.

It was also suggested that the cohort data set could be stratified by address. This would enable all members of a family living in the same household to receive the information at the same time. This was also brought up by one of the patient interviewees who was concerned that family members had not received the survey because they did not all receive it at the same time.

### Communication routes

The initial project design had three communication routes to deliver the survey to patients; these were SMS, email and letter. During the initial planning stages, it became clear that both SMS and email had significant problems which were not surmountable. These were discussed at interview.

#### SMS

It became clear that the current functionality of SMS messaging was unable to support the type of survey that was planned. Only limited information could be sent via SMS, the richness of the information was minimal, there was no ability to insert hyperlinks and it was not known which mobile phone numbers held would support 'smart phone' technology and which were *'Nokia bricks'*. It was suggested that if this route was used in the future, a 'pre-campaign' to update contact methods and potentially download a specific app would be required to facilitate this type of survey questionnaire.

#### Email

Utilising email as a delivery method also proved problematic. In addition to the search revealing only 15 email addresses which appeared to show permission to use, ethical concerns were raised. These included multi-person email addresses, currency of the email address, the lack of encryption and no specific policy or procedures to guide its use. Therefore, email was abandoned as a delivery route.



### *Drivers and inhibitors*

The wider drivers for the updating of the contact methods aspect of the project were seen as efficacy and efficiency. It was hoped these improvements would reduce cost, improve communications, and reduce miscommunication and complaints. The patient interviews endorsed the view that communication modes that move towards cutting costs are supported.

Drivers for the research permission section of the project were perceived as increased ability to identify patients interested in research, which could lead to increased recruitment and rapid uptake of research opportunities. Conversely, the barriers to completing this type of work in another setting were identified as inertia, lack of interest, workload, and the fragmented nature of NHS digital systems.

Discussions were entered into whether incentives could be used to increase engagement by primary care. It was thought this could be utilised; however, caution was expressed. That caution centred on patients being 'turned off' by practices being paid to find research participants and that payment was contrary to the altruistic motives which patient interviewees stated for taking part in research. These thoughts link back to both the reasons interviewees expressed for taking part in research per se and also the reasons the patient participants gave for declining contact from commercial researchers. There is a feeling that overt commodification of the recruitment process in primary care could potentially dissuade patients from recruitment.

A single dynamic medical record and permissions platform was regarded as the ultimate goal. However, the complexity of the permissions, information and digital interfaces were seen as major inhibitors to this scenario.

### *Outcomes and findings*

Both staff participants had expected the response rate to be 10% or below. They were surprised at the 24% response rate. It was thought that the updating of contact preferences with the practice had been quite a draw, although this was not borne out in the patient interviews. However, both the staff and patient interviewees suggested that the relationship between the practice and the patients had affected the response rate in a positive way. An unexpected additional finding was that a large proportion of those who completed the survey via their online account also completed the 'Friends and Family' questionnaire at the same time. These were all completed with a favourable view of the practice. This again links back to the patient interviewees who expressed a desire to give something back to the practice and also feelings of autonomy and empowerment gained by being asked their views.

There was an expectation that SMS would be the preferred contact method, and that this was a positive outcome from the project. However, reflecting the patient interviews, there was an understanding that there are those who for their own reasons will continue to require and prefer communication by letter.

Whilst it was felt there would always be a group of patients who would respond NNN and the number who did was not a surprise, a view was expressed that the number who said yes to NHS researchers contacting would have been higher.

It was thought that the large proportion of respondent who refused access to their anonymised data by the researcher had not understood fully the request to access. It was also suggested this could have been off putting; sounding 'scary' and the default position was just to say no. The lack of response via the online account was thought to be convenience based. It is easier to return a pre-paid envelope than login to a specific account. Related to this, the 40% of online responders being over 60 yrs. was seen as those who are most familiar with the online platform and its use.

The lack of overall response from the 18-29 yrs. group was explored. Reasoning for this finding included lack of interest in health-related matters, lack of concern regarding 'consent' as a whole, and the 'what's in it for me' scenario.

Overall positives from the project were seen as the information gained regarding contact method. SMS is free and appears to be well supported by patients, both those who indicated it was their preferred mode of contact and those interviewed. In addition, it was hoped the project would facilitate speedy and efficient recruitment to research studies.

Both interviewees thought the project was feasible to carry out in a general practice as it had minimal impact on the wider practice team. The feasibility was linked to adequate financial reimbursement to allow the updating of clinical systems, data collection pre and post the survey, data inputting and administration time required.

In summary, the staff interviews indicated that the level of impact on the practice as a whole was far less than expected. The processes required to complete the project took longer than initially thought but were minimal in their overall impact. The overall response rate was positive. The wording of the original information may have been off-putting and could be a reason for non-response.

Recommendations were made regarding the updating of the eligible cohort dataset. The gain for the practice was seen as a mandate to expand the use of SMS as a contact method. However, this is currently limited by the functionality of the systems in use. Email contact requires further detailed processes.

## Discussion

When discussing the findings of this project the response rate to the postal survey needs to be taken into consideration. Postal questionnaires are currently widely used to collect data [33]. Response rates to survey questionnaires in the general public rarely exceed 50% [34]. Non-response reduces the validity and reliability of the results and introduces response bias. However, although limited, some general conclusions can be drawn and correlations suggested.

Strategies that may increase the response rate in any further work need to be explored. Due to time constraints a reminder or second mail-out was not utilised in this study. In addition, the amount of information sent to the survey participants could have been seen as off putting; however, no further information was sought by the interviewees before they returned their survey form. It may be worth employing more signposting of additional information in any future project which could reduce the length of the material which accompanied the survey form. It could also be beneficial to send out postal questionnaires stratified by address. This may prompt interest and discussions within households, and increase the number of surveys returned.

Whilst it was felt that updating contact details may have been an incentive to return the questionnaire, those who non-responded were not motivated by this. Those who were motivated to return the survey questionnaire were on the whole older and female. It could be suggested that those who are utilising health services either individually or with aging family members were more inclined to respond. This was borne out in the patient interviews where there was a desire to give something back to both the practice and the wider NHS. The younger demographic have not been as exposed to illness or chronic conditions and therefore do not feel involved enough to want to reciprocate help to the health care systems. It was not thought that the aspect of giving permission would put off the younger age group. All non-responders in some way did not perceive enough gain to elicit a response. Better articulation of the potential positive outcomes may have prompted more responses, although as no non-responders or NNN responders volunteered to be interviewed this is difficult to say.

Further areas that may have impacted on response include misunderstanding. Interviewees thought the project was primarily about communication with the practice and the wider NHS. The recruitment to research was a secondary consideration. Using the survey to collect responses to questions about preferred contact method with your general practice, permission to pass your contact details on to researchers and to give information about routine data use appears to have muddled the aspects and caused a degree of conflation of the ideas. The lack of clarity of understanding around the routine use of general practice data has previously been noted [35] as has

the disconnect between short term improvements and long-term gains. This may in some way explain why some of the patient interviewees suggested data could be used to track non-attendance to practice appointments. If the potential respondents were unsure about the project's scope and purpose it seems logical to assume, they would lack commitment and engagement [36]. Any future work would need to explore strategies to further differentiate the strands or potentially split them entirely.

Findings from this project suggest patients who are currently using email on a regular basis would be happy to communicate with their general practice via this route. Email is not popular with the younger demographic, rising as a choice to a peak of 30% in the 60-69yrs. age group. It also appears that most of those who indicated email as their preferred mode of contact have validated their email address with the practice after the survey. However, from the perspective of the practice there are significant issues with the use of email as a communication method. The issues identified are reflected across the literature with concerns about security, confidentiality and governance raised [37]. Policy and procedure need to be formulated and implemented across primary care as a whole before email is adopted as a standard method of communication. While the use of email could be seen as improving digital connectivity the number of online accounts made in the 12 weeks prior to the survey period is on parity with the number made during the survey period. Therefore, the project does not appear to have prompted patients to open online accounts.

SMS messaging is seen as the contact method of choice by the responders. Caution also needs to be used when adopting SMS as a standard method of communication. Patients find the 'text reminder' a useful addition but it is not known how acceptable SMS would be if its remit was enlarged. The current functionality of clinical primary care systems limits the richness of information sent via this medium. It may be that commercial companies who are currently occupying this area in the health setting move this forward using App technology. It was previously thought that the NHS App would take on this role but recent reports have suggested this may not be the current vision [38]. The acceptability of the scope and use of SMS and email requires further exploration.

It must also be noted that a large proportion of the responders who were 70 yrs. or older preferred letter as their method of communication. It is also worth noting that, of those whose preferences data was supplied by the practice, 49% chose letter as their preferred method of communication. Whilst digital communications are currently at the forefront of monetary savings across the NHS, there will always be a requirement for information to be available in paper format. Paper carries with it notions of personalisation and commitment from the sender to the recipient. As paper communication is withdrawn there is a potential for certain cohorts of people to become

marginalised and hard to reach. The functionality of preference setting tools needs to be dynamic and individualised to allow the person to choose the most appropriate method for their circumstances.

84% (n=632) of the respondents who gave permission for the researcher to access their data gave permission for NHS researchers to contact them. However, when taking into account those who declined the researcher access and the overwhelming NNN (82%) responses in this group the two polarised views of either YYY or NNN were the most common choices. This could suggest that granularity of permissions requires further work to explore the underlying rationales for choice. It is notable that in the 70+ age group, those who responded NNN are predominantly women (whereas men are in the majority of those who responded YYY). It could be suggested that these women, due to historical factors, such as education and employment, are less confident with information technology and therefore mistrust data sharing activities. When correlating the NNN response to the preferred method of contact there is an implication that there may be a cohort of people who are predominately woman, who are not willing to data share and are not willing or able to engage with electronic communication mediums.

The trustworthiness of the NHS as an institution was correlated to the positive responses. Mistrust was associated with the actual word 'commercial', its construct including many negative notions or discourses. This social construction of situations or collective groups is well documented [39]. They are known to contain conflicts and contradictory ideas or discourses which are both supported and silenced [40]. These discourses have the power to co-construct and shape societal norms, values, expectations and fears. Silencing in this project is seen in the patient interviews where the interviewees failed to recall any digital or data issues with the NHS. This was despite the research being set shortly after the WannaCry cyber-attack which was reported to have cost the NHS £92million and caused the cancellation of 19,000 appointments [41]. Interviewees suggested that the NHS operated with high levels of up-to-date cyber security, this being one of the reasons why they trusted this organisation and its researchers to contact them. Where negative comments were made, they were linked to medical issues and rationalised as human error and forgivable. In contrast, reflecting the known reticence to data share [14] [15], a myriad of negative issues with digital and data communication could be recalled and linked to other organisations and social media platforms. Added to this, the patient interviewees did not as a norm utilise social media platforms, they were construed as having a negative impact on society as a whole. Several patient participants discussed political views and certain media outlets. These were on the socialist side of the political spectrum, associated with anti-commercialisation and anti-privatisation. The positive support for the

NHS as an institution was reflected onto current political controversies and their portrayal in the media. It is therefore not surprising that those interviewed expressed views of trust for the NHS and mistrust towards any degree of commercial activity. Their own values were shaped by their instinct that the NHS was trustworthy and their fears were driven by perceived attacks on that trustworthy institution. The contradictory notion of their norms was aptly illustrated by their understanding that partnership working with commercial research organisations does occur in the NHS, but they were still reticent to share their personal information with those same commercial organisations. Further work is needed to better articulate the positive aspects of joint research projects. It is suggested that should this project be repeated the word 'commercial' be replaced.

Linking to the above is the notion of reciprocity [42] [43], the giving something back, the treating others as you would expect to be treated. For patient interviewees the taking part in this project was expressed as a giving back. The reasons they felt the desire to give back were associated with altruistic motives but also a way of expressing gratitude to the practice and the NHS. In addition, all spoke of cues to action [44], a trigger which prompts engagement. These were personal illnesses and chronic conditions and the thought that aging leads to more illness. Following on from this, the participants thought they could be involved in primary research that would focus on their specific illnesses or wider health promotion. There was a perception that being involved in research could lead to diagnoses of illness and better health outcomes. This perception has been recorded before in clinical research and is associated with the idea of therapeutic misconception and therapeutic optimism [45] [46]. It is expressed as an over-estimation of the positive consequences of participation in research and persists despite explicit information to the contrary being given in the consent process. From this it can be seen that reciprocity is a circular notion and that while those responding positively to the permissions request did so out of an altruistic notion, there was, however a tacit understanding that they may 'get something back' from taking part in research. It needs to be noted that when comparing the permission choices with the presence of a long-term condition there was no significant correlation with the choice and having a long-term condition.

Finally, it was interesting to note that staff participants felt that overt financial incentivisation of primary care to recruit research participants could be counterproductive. It was felt this commercialisation or commodification of the recruitment process would be in conflict with the reciprocal and altruistic motives cited by patient participants. The same rationale was given by patient participants for declining commercial researchers' access to their personal contact details. Add to this the anti-commercialisation and anti-privatisation rhetoric expressed by some participants and the willingness to enter into behaviours which are perceived as money saving and it is clear that

the NHS remains a pivotal part of British Society for this group of participants. The core values of being 'free' and 'for all' are still highly valued.

From the above discussion, conclusions and recommendations can be made.

## Conclusions

The project was acceptable and feasible to carry out in general practice with the level of financial assistance offered. The SIP and associated research project had minimal impact on the practice staff. Two main personnel were involved in the SIP and production of baseline and post survey statistics. The main gain from the practice's perspective was a mandate to continue to use SMS messaging and explore ways of further developing its use. Email contact remains problematic and requires further detailed processes before it can be adopted as a general practice based method of communication. It could be suggested that any change to a social media type of platform would not be welcomed by patients as this medium has high levels of mistrust attached to it.

From a patient perspective the updating of personal communication preferences and data sharing preferences via this project were acceptable and feasible. However, the degree of non-response needs to be taken into consideration. It is difficult to suggest strategies to overcome non-response as this group was not represented at the interview stage. A reminder or second mail-out may elicit further responses, as potentially would reducing the length of information and splitting the updating of contact details from the data sharing permissions.

The main influences on choice of communication method were ease of use and familiarity, plus a desire to be financially prudent on behalf of the health care organisations. The strongest influences on data sharing permissions were levels of trust and mistrust and the perceived benefits from engaging in research. All choices need to be recorded in a way that allows the individual to control and change the settings in line with personal circumstances.

Permission to contact by researchers was gained from 15% of the eligible practice population. When exploring if this work would aid recruitment to research from primary care, we can draw some general conclusions. The older demographic would be more likely to volunteer to take part. Studies conducted in health promotion and chronic disease may recruit better from primary care. Projects set within the NHS and academia would be trusted. Where contact came from commercial organisations alone, recruitment may be adversely affected. Overt financial incentives may act as a barrier to recruitment.

Whether the project can aid recruitment cannot be fully assessed until the practice engages with a research study as a recruiter. Therefore, whether the project represents value for money for the funders is as yet hard to quantify. It is suggested that a response rate of 24% does not make this an acceptable option in terms of building a registry of patients. The project was however, acceptable and feasible to carry out from both the practice and patients' perspective. Non-response has impacted on the validity and reliability of the conclusions and correlations drawn. However, the interviews support the general trends from the statistical data.

## Recommendations

- In any further iteration, strategies to reduce non-response should be engaged with.
- Splitting the component parts of the project into individual studies may aid understanding and engagement by the eligible population.
- Further work is required to explore the scope and acceptability of SMS and email contact.
- Additional work is required to explore the granularity of permissions and the rationale for choice.
- Overt commercialisation of the research process may hinder recruitment.
- Studies in primary care should be targeted at health promotion and chronic disease.
- Further work is required at a regional and national level to better articulate the role of commercial companies in NHS research.
- Further explore the value and test the outputs from this study by using the practice to approach patients about relevant research. This would facilitate an assessment of the willingness to engage with researchers, when compared with routine response rates from general mail-outs in primary care.



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## Appendices

### Connected Patient Project: Information sheet

#### What is the Connected Patient Project?

Firstly, we are asking you how you would like the surgery to contact you about routine health matters. A lot of people like to be contacted using text or email. They find it quicker and more convenient. We are giving you the opportunity to state what your preferred way is. Please show your preferred way on the enclosed Choices Form.

Secondly, we are also asking you if you would like to be contacted by certain teams who conduct health research. To help you make your decision about being contacted by teams running research, we have produced some additional information. Please read it and feel free to discuss it with family and friends before you make your choice. Please understand the choice is yours. Whatever you decide it will not affect your rights or medical care from the practice.

#### Contact by Research Teams

We are setting up a new system to improve the access to approved research projects for our patients. Research helps to improve treatments and services. It may or may not benefit you at the time if you participate, but it may help future generations. In some cases it can mean you are monitored more closely, and get access to new treatments. Taking part in research can also mean you feel more in control of your health.

There are different teams that often conduct research. You may be happy for your personal details, such as, name, address, age range and details of medical conditions, to be given to these groups. The teams typically include:

- NHS researchers, such as hospitals and general practices
- University based researchers
- Commercial researchers, such as drug companies and companies who make equipment used in health care.

We would only share your details if you have given us permission and if the research was relevant to your health history. An example of how this works could be: A university contacts the practice about research they are doing into falls prevention. They would like to carry out the research with people who are 65 years of age or older and have poor vision. We would then search our computer systems for patients aged 65 years or over with poor vision who have agreed for their personal details to be passed to university-based researchers. We would pass on the contact details to the researchers, who would then contact that person directly.

By agreeing to be contacted you would not be agreeing to the research, just to hear about the research. You would always be given the full facts about the risks and benefits of the research before you decided to take part. It would not affect your medical care should you decide not to take part.

You may be happy to be contacted about research by some, but not all, of the teams. If this is the case please show that on the Choices Form.

**We would never share your information in this way unless you have given us permission.**

#### What happens once I return my Choices Form?

When you have returned the form, we will update your medical record with your decisions. In the future when the practice contacts you, we will aim to use your preferred method first. Additionally, if the practice is asked to take part in research and it is relevant to you and you have agreed to be contacted, we would pass on your contact details, so the researchers could contact you directly. By returning this form you are giving us permission to update your medical record to show the choices you made.

As this is a new process an NHS researcher called [insert name] is based in the practice. She is going to look at the choices people made to see if there are any patterns. To do this we will look at your age range, gender and medical history. We will then let [insert researcher's name] see this information in an anonymous way. This means that anything that could identify you is removed. This is so she can see if certain groups of people make the same decisions. An example of this would be: 50% of women aged 40-49 years agreed to share their information with all the groups. Another example would be: 30% of men aged 30-39 years preferred email contact. By returning the form to us you are giving us permission to use your anonymous information. If you do not want your anonymous information used please tick the box on the Choices Form.

[insert researcher's name] would like to hear people's views about this project. She would like to interview up to 30 people about the Connected Patient Project. She would also like to talk about the information we sent to you and the reasons for the choices you made. She wants to know your views about being contacted by organisations for research purposes only. Even if you have decided not to share information with any of the groups [insert name] would still like to talk to you. We hope this project will be carried out in other General Practices so your views on how to improve it would be very welcome.

If you would like to talk to [insert researcher's name] you can contact her directly on: Email [...] Phone [...]. Or leave a message at the surgery and she will contact you.

### **Do I have to return the Choices Form?**

No you don't have to return the form. If you do not return the form your care will continue as it is now. However, your views are very important to us and even if you do not agree to be contacted by any of the groups we would still like to hear from you about the way we contact you. [insert researcher's name] would also like to talk to you about why you chose not to return the form. You do not have to take part in an interview. The choice is yours and optional.

### **Can I change my mind at any time?**

Yes, you are free to change your mind at any time. Just contact the reception staff or if you have a SystmOnline account you can change your choices there.

### **Is there any other information available?**

Yes, there is some information enclosed about what already happens to your personal information. We have put some information on the practice website at [insert link] about how information is used to improve care. This information is also available from the reception staff.

After reading this and the additional information, if you still want further advice before you make your choices please contact the practice manager [insert details].

### **What do I do now?**

Please fill out the Choices Form and return it to the practice. It can be returned in the pre-paid envelope supplied or in person. If you have a SystmOnline account you can fill it out by accessing your own account.

**Thank you for taking the time to read this information and filling out the Choices Form.**



## Your Medical Information

All the information we have about you is stored in your medical record to ensure your care is safe and effective. It is very important you trust us to keep this information securely and only use it as you want it used. We believe that sharing your information appropriately is very good for you and the NHS and Social Care System. We know that some people are nervous about sharing their information. Here we explain how we share your information.

### **Sharing your information to help look after you.**

Patients want and expect us to share their health information with other NHS and Social Care staff that are looking after them. This might include hospital doctors and nurses in clinics or out of hours, physiotherapists, chiropodists and community nurses. Unless you have told us not to, if they are involved in your care we already allow these individuals to see your information. They will ask you for your permission before they look at the information. If you want to stop these health professionals seeing your information, please let us know. It is important to note that your care from these health professionals may be delayed or may not be as good if they cannot see key medical information about you.

### **Sharing your de-personalised information to help improve health and social care systems.**

De-personalised information means your personal recognisable information such as name and address has been removed, hidden or coded. Most patients are happy for their de-personalised health information to be used to improve the NHS health and social care systems for everyone. Examples of this would be: Organisations such as NHS England requesting information on how many people of a certain age take a certain drug. Or a report produced and shared about the average blood pressure of those taking medicine for high blood pressure. These types of facts are used to improve health and social care, access funding and monitor practice performance. We only share this information with people and groups that follow the same privacy rules as we do. In this case we **never** give anyone your name, address, date of birth, or contact details. We do not give this information to insurance companies. Unless you have told us not to, we already share your de-personalised information to improve the NHS and Social Care systems for all. If you want to stop these groups seeing your de-personalised information, please let us know.

### **Sharing your information is occasionally compulsory**

There are a small number of situations when we have to share your personal information, even if you disagree. These include if you have contracted certain infections; a court order; to prevent serious harm to children or adults.

### **Controlling how your personal information is used.**

There are many ways for you to customise how your information is shared. You can opt-in, opt-out or customise many of the information shares. **Please contact the surgery if you would like to discuss this in more detail.**

**Connected Patient Project: Choices Form**

**How we contact you.**

My preferred way for the practice to contact me about routine non-urgent things is: (Please **tick one** option).

Email       Text       Letter

Please add the email or text number that you would like us to contact you on below or note any changes to your address.

.....

**Contact from researchers.**

**I give you permission to share my personal information with NHS researchers so they can contact me about research (tick your option)**

Yes       No

**I give you permission to share my personal information with university researchers so they can contact me about research (tick your option)**

Yes       No

**I give you permission to share my personal information with commercial researchers so they can contact me about research (tick your option)**

Yes       No

We want to understand why people make these choices. A researcher based at ( ) Surgery called [insert researchers name] will look at the anonymous characteristics of people making different choices. If you do not want [insert researchers name] to look at your anonymous information please tick the box below.

I do not want the researcher in the practice to use my anonymous information.

**Please add your name and date of birth:**

**Name**.....**Date of birth**.....

**Thank you for filling out the Choices Form. Please return it to the practice.**

**Appendix II: Activity Analysis Tool**

Date	Query and outcome	Time taken (minutes)	Initials.

## Appendix III: Interview Topic Guides

Topic guide Staff interviews.

Review the role the interviewee has in WP1.

Frame the questions around the role of the interviewee.

Explore the main aspects of that role.

Seek out examples to describe the impact on their role of WP1. (Use findings from activity analysis tool)

What are the most common recurring queries.

What information/help do you have in resolving those queries.

What with your experience would help the process if it were repeated.

Anything else you would like to tell me.

Topic Guide: Patient Interview.

Opening with general welcome and introduction.

Use the WP1 material as prompts.

Understanding of WP1.

What did the participant think it was all about.

Did they seek out further information to inform their thinking.

If they did was it enough, what else was needed.

Was the contact from the practice the first they had heard about the preferences project.

Explore where they saw/heard about it before. Did that influence any decisions.

Did they talk to anyone about the project, if so who and what did they talk about. Did that influence their decisions

How did they receive the information from WP1 (SystemOne/Letter)

How appropriate did they feel that was

How did they get their response back to the practice

How easy was that process

How could it have been done better

What other information should it have contained.

What choices did they make

NHS

Universities

Commercial organisations

What experience of research do they have

How important do you think it is to be able to take part in research

What things do you think about when someone mentions data sharing to you.

What information are you happy to share

What information would you be unhappy to share

What influenced any different decisions

Are different organisations more trusted than others

Why, what is it about that organisation compared to another.

How do you decide who you trust and who you don't.

What things could be done to increase trust

Alternative consent phrasing

Are there some organisation you would never trust with your personal information

why

What choice did they make about contact method

Email, text, phone, letter

What were the reasons for making the choice they did.

What problems if any can you see for the methods not chosen

Would you recommend this process to a relative/friend if it were offered to them from their GP

Why/why not, what would make you recommend it

Have you got a secure Systmone account, have you ever thought about having one

What do you think are the advantages of this / disadvantages

How important is it to you to be able to change your own permissions.

What else would you like to be able to do yourself regarding your information.

Have you made any changes about your personal information settings since the 'facebook' incident

If so what and why

Anything else to tell me you feel is important.

## Appendix IV: Table Illustrating Themes

Themes from the patient interviews		
Theme: Understanding	Codes	Supporting text
	<p>Communication between patient and wider systems. Conflation of ideas.</p>	<p><i>I formed the impression that it was improving communication between the individual, the patient and the system. (LG003P)</i></p> <p><i>I had to read it a couple of times, and I thought basically it was about communication between the surgery and the patient and how that was best carried out. (LG007P)</i></p> <p><i>I thought it was just general admin really, asking how they would, what my contact is, and then I wasn't too sure about the researchers' bit. (LG008P)</i></p> <p><i>What I thought it was about was about extending research, so the form, there was a fair bit of detail about confidentiality and other things, but the gist I thought was about basic research and I took it to be expanding the ability to gather information, so that's what I took it to be about. (LG002P)</i></p> <p><i>...there's been some adverts on the tele, well I think it's relating to better patient access, different like, you can talk to a doctor on skype, and I took this as something roundabout, to improve, if they can the service that they give. (LG006P)</i></p> <p><i>I thought it was about improving both practice and my, or our patient participation with the practice. I didn't know. but in my mind I had a number of ideas, when I use the practice, probably seasonal, when I use the practice, my record, I imagine I've given that permission, so my record from when I was born to the current day and anything in between. NHS researchers, first thing I thought yeah not a problem with that, its NHS, its relevant, it's my data, but its NHS so whatever's in my data, I knew it would be redacted, whatever was used, it would be helpful, I didn't know what things it would help, patient interactions, it might be treatments, I don't know, I don't know what data would be used. Then I got onto the university researchers, erm, I can see the interaction there type of thing, and then I got to the commercial researchers and the first thing I thought is selling data, somebodies making money out of my data.(LG005P)</i></p> <p><i>...well what I didn't appreciate was that the means of communication was the purpose of the research I thought the</i></p>

		<i>project was something else, like putting my name forward for something else, something else like disease or drugs or something. (LG001P)</i>
	SIP information	<p><i>I thought it was quite wordy, I thought there was quite a lot of it and you had to sift through to find out what it was about. The things I remember most about it was the stuff about there being no obligation and the stuff about it being anonymous that you can withdraw, rather than what it was actually going to be asking about.</i></p> <p><i>I still feel that the point of the exercise is lost in the procedural information. There you go (turning the page) it's off putting, there are such a lot of words. If it was shorter you might have got more back (LG001P)</i></p> <p><i>I thought it was quite long winded, but it has to be, so I understood that, I thought it was a good idea and I didn't see any reason why somebody wouldn't want to participate. I think there is a danger if someone, even if it's 5 pages long as it was, there's a danger some people look and think it's a bit boring halfway through and some people put it down and you don't get a phone call, there's a chance of that. (LG002P)</i></p> <p><i>Possibly could have been summarised a little bit shorter. (LG004P)</i></p> <p><i>...to be honest, I read the first page and I oh I can't be bothered with that, it was a couple of days later that I referred back to it, read and if I can help them improve the service or whether it's meant to help I thought I'll do it. All the pages to read, I've got to do it when I am in the mood, not, cause if I hadn't of read it all and just filled in them things I probably wouldn't be sitting here. (LG006P)</i></p> <p><i>I think there could be more clarification on what the researchers could be contacting you about. I think if it did that it would make it a bit clearer. (LG008P)</i></p>
	Use of paper	<p><i>because I think I bit more effort goes into printing stuff off, putting a stamp on and all that, and because I don't have to be sitting at my computer to be scrolling through it, I could read it at my leisure on my sofa. It's just it feels like more effort has gone in, it's easier to deal with afterwards for me (LG001P)</i></p> <p><i>It sort of makes you look at it, because it does look so professional, it does look... it makes you engage with it, I've got to read this. (LG005P)</i></p>
	Evidence based	<i>Because I think good decisions about changes in anything should be made on the basis of research, especially the recipients of whatever the service is in this case. I dislike decisions that are made by pen-pushers, managers in offices;</i>



		<p><i>I've got time for decision that are made after consultation.(LG001P)</i></p> <p><i>Just raising awareness, rising knowledge, not living in a state of ignorance. Life is very complicated and medicine is extremely complicated and extremely expensive and choices have to be made about, are you going to buy somebody a drug that costs a hundred thousand a year when we are so short of so many things, it's a dilemma. (LG003P).</i></p>
	Data sharing	<p><i>...my simple view is that if people aren't sharing information and you haven't got the ability to do that how are you ever going to develop any medical improvement, you have got to be able to combine everybody's information otherwise you are in silos looking at people's information. (LG002P)</i></p> <p><i>...well I know it's secure, it's in my notes, it's not shared willy-nilly, it's not being bought by the pharmaceutical company. (LG003P)</i></p> <p><i>You know we all have trouble with people ringing up, I was a bit wary about that, but if I knew it was coming from a proper researcher, which I have given permission for I've got no problem with that. It's all these other phone calls you know we all have problems with. I don't think things will ever be 100% sadly but you know I think in life there is risk and you've got to balance those up. (LG004P)</i></p> <p><i>I can see the value of that as long as it's anonymous, in that sort of setting I can see the value yes. (LG007P)</i></p>
Motivation	<p>Types of research:</p> <p>Cues to action</p> <p>Therapeutic misconception and therapeutic optimism</p> <p>Limits</p>	<p><i>...you've got the age-related stuff you know, I'm a male over 50, so you know there are lifestyle things, general health things, so I thought it would be pretty all encompassing so I for all there might be some specific stuff there might be general as well. There is certain things in my family history if the knowledge had been better people might have been able to live longer or whatever, had certain treatments, it's really down I guess partly to generic improvement and partly personal improvement, cause there might to somebody contact me about something I've got that might help me in the long term that I know nothing cause you don't know what you're talking about do you. Something might help you long term, but ultimately it's about just sharing information and I don't see any harm in that. (LG002P)</i></p> <p><i>Well I presume, relevant to my age, my health situation, what am I doing about controlling my blood pressure (LG003P)</i></p> <p><i>Well I think just to ask things about your personal medical history, or anyway I could help with my experience of 55% lung, living with that all my life. Is there better ways of managing it, you know I don't know how, whether it's more drug related research or the physical side. (LG004P)</i></p>

		<p><i>...probably illnesses, research into lifestyle, so history, medical history, or those types of things. (LG008P)</i></p> <p><i>oh god, well I certainly wouldn't want drugs tried out on me, or anything like that, I don't mind being asked questions, I can't imagine really what it might involve. (LG009P)</i></p> <p><i>I don't think I have got anything I am embarrassed about, no particularly not that I can think of. In a generic sense such as this I cannot think of anything (LG002P)</i></p> <p><i>I mean historic data I've not really got that much of a problem... I think what's in the past is gone (LG005P)</i></p>
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Theme: Motivation	codes	Supporting narratives
<p>See also: Types of research: Cues to action Therapeutic misconception and therapeutic optimism.</p>	<p>Reciprocity and altruism</p>	<p><i>I'm very fond of my GP practice and anything I can do to assist them I feel is like a reasonable exchange for the services they offer me. (LG001P)</i></p> <p><i>Well I think it's a very good doctor's practice, I think they are excellent really... think they are a very good doctors really. (LG009P)</i></p> <p><i>...suppose me reason for doing it is simple if there is an opportunity to improve anything medically people should be obliged to do it really. (LG002P)</i></p> <p><i>To make progress to improve the nation's health, the more information you have, the greater awareness you have, so it's better, or people would be living in the dark.(LG003P)</i></p> <p><i>My first impression was that doing any research is helping the future generations. I read through it and I felt quite comfortable with what it had to say, yes, I think that's about it. (LG004P)</i></p> <p><i>if you don't go down the route of this, it is difficult to improve things you're just going to stay alike and it's just more people and less practices time, it's important, we know what pressures the NHS is under, its well documented, I think there's not a person in the country that doesn't know the NHS is struggling so anything that can help improve. (LG005P)</i></p>

		<i>Research to me, in my opinion or, how can I put it, could help another person with either one of my conditions, that's why I said yes. They (NHS) have helped me stay alive all these years, and if I can help some other people, may be they've done something wrong, not wrong but like, they can now do it a different way. Like I say I've had that many operations, and I'm in 4 different clinics at [hospital name], and like I say, just giving back....NHS has kept me alive for all these years, I'm on I don't know how many tablets a day and if I can just give a little bit back with me trust not being abused. (LG006P)</i>
	Improved personal health outcomes	<i>I am where I am in life and I just think basically is there anything I should have had that I didn't. It's purely that bit of nosiness, bit of need to know, I think it's just making sure I've had all the inoculations what I could have had, should have had. ( LG005P).</i>
	Views on health care systems.	<i>I also feel quite strongly about the NHS, the way things are going and you know I would do anything to try and keep it, but I am very against the contracting out of things and also obviously the private, the push to privatise everything, I feel quite strongly about it. (LG009P)</i>  <i>I get the Guardian, so you can tell my politics; I'm not exactly right of centre. The likes of the Virgin man suing the NHS for a billion because it's not competitive and all that nonsense, so I'm on the side of the good guys, put it that way. It's a fundamental, education and health, should be universally available and of a decent standard. (LG003P)</i>  <i>I am a big believer in the NHS. I think it's marvellous. (LG008P)</i>
	Empowerment	<i>...a patient project and patient participation I felt quite, I'm going to say something here, going to put something down on paper, and somebodies going to listen. I didn't know what it was until I read through the info that's contained in it; it felt like your part of the practice type thing, so yeah. There was a feel good factor if you like. I feel quite empowered really, that somebody has spent time to listen to the point of view, thank you, I don't know what difference it will make but it has been really good. (LG005P)</i>  <i>I just thought it was some involvement with the practice, so I thought it was quite good that they were asking about what I thought. (LG008P)</i>
	Communication choice	<i>Had it not been for the cost of postage letter would have been my choice, but I know the cost of postage and email is an easy second choice so we'll go with that. But yes, I can see that idea of that. (LG007P)</i>  <i>I thought it was a good idea, (the project), partly just the how you contact, I thought was quite good...to save</i>

		<p><i>money for the NHS, so that was about all. I hadn't realised until recently how much a stamp is. (LG008P)</i></p> <p><i>I do look at all my email, I know some people let them build up, I don't mind text, letter I just find long winded when you can email, so I think I'm guessing I put email, if I'm honest I cannot remember. (LG002P)</i></p> <p><i>I put down email, text or whatever, its' just that emails cheaper than sending a letter and text, I could have put both, but it said select one. (LG003P)</i></p> <p><i>I think I said text, I'm very happy with that, it's one skill I do have, I text, I'm not even sure if I ticked the email, but I'd be equally happy with the email, but text I'm more likely to check me texts regular. (LG004P)</i></p> <p><i>I would have put email, letter there's the time side of it, it's my little bit of saving the planet, another letter, and I know emails will get read, but I'm conscious of the fact that not everyone will have a computer or access to emails so you have to cover all bases, but I would have put email. (LG005P)</i></p> <p><i>I don't use a mobile phone, so text isn't an option, and phone can be quite difficult sometimes, where as I check emails regularly so it seemed more sensible. (LG007P)</i></p> <p><i>Oh I put email I think, I think I did, I did think about putting text cause I love text messaging, I do check my emails. I just think it's easier than letters really. I mean I love snail mail me but I can see how email would be very useful in a doctor's practice. (LG009P)</i></p>
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Theme: Trust and Mistrust	Codes	Supporting Narrative
	Trust of NHS and University. The elements required. Silencing of issues.	<p><i>In simple terms not for profit, in a nutshell, it's not for profit, so you feel it's been done for genuine reasons, it's been done, someone is putting the effort in, Ok it's got to be funded, but they're not openly just out to make a couple of quid.(LG002P)</i></p> <p><i>well, it (the NHS), has integrity, public spirited, it's for all people, whether rich or poor, yes it makes</i></p>

		<p><i>mistakes, my sister had a very poor diagnosis years ago, her GP diagnosed a burst appendix and the surgeon at [local hospital] say no and subsequently it burst, and she's had horrible health consequences since, it's not infallible, teaching is not infallible, you know, even if you think you've been a good teacher you know you make mistakes, so you know, we all make mistakes, some are more competent than others, more honourable than others. (LG003P).</i></p> <p><i>Well I think purely the medical involvement, NHS research, university research, you know I've done a university degree me self and I knew how helpful it is for people to respond and how unhelpful it is when people don't want to. (LG004P).</i></p> <p><i>I trust doctors, I trust the NHS, my [relative] used to work for the NHS and [they] might have a different opinion. But I just feel as though you should trust them...I assume though I may be wrong that the NHS is actually doing the same,(talking about updated IT security systems) and that practices are as well. I just take it for granted that they will be, I know everything we do is so I just assume they are, so I hope they are. (LG008P)</i></p> <p><i>Gut feeling I think, it has to come down to, for me, despite the horrible documentary I watched on the TV last night about horror in some hospital I trust the NHS, I think it is a wonderful thing really, I do trust the NHS. (LG001P)</i></p>
	<p>Mistrust of Commercial organisations.</p> <p>Gut instincts</p>	<p><i>I ticked yes for the first 2 and no for the third. And I think that is just probably a fear of spam, getting contacted by people who are not really interest in the people who are for true medical development, but are more interested in selling you something. That was why, that might be unfair but it's a gut reaction, as soon as it said commercial research, I was like well no not really cause that's more for somebody making money than medical. I know they go hand in hand as well but it's just a gut reaction. I could probably be persuaded otherwise but. As long as its limited, I think I am happy sharing in a true medical environment, you mentioned NHS, you mentioned medical research funded by the NHS, I think the only time I'm not comfortable is when it goes commercial, I don't particularly want somebody contacting us to do medical trials that's really about a profit organisation more than a medical organisation. That's where I get a bit uncomfortable, so I'm very happy to do anything for true medical development, and I say it's a contradiction cause I know a lot of it is funded privately anyway, but that's another branch again in my head. (LG002P)</i></p>

		<p><i>I think the word commercial. Commercial I think it's lording it out and I'm not quite sure as to whether it would be wise to commit to that. Commercial. (LG004P)</i></p> <p><i>I know what companies like [company name] are like for data mining, so I'm thinking NHS data is going to be sold onto another party and somebodies making money from my data and somebody like [company name] who cannot help themselves to get as much data from the world as possible for their own uses, so I'm not going to agree to that, commercial researchers...that is my gut, I didn't fill the form out on that bit straight away and I tried to talk myself out of it and I couldn't, so it was just purely that, people making money out of, but it's totally probably wrong, I think it's the word commercial, I link commercial with somebody making money. (LG005P)</i></p> <p><i>Who do you trust the most? I would put The NHS there, and because I've never had anyone contacting to say I've lost your data. (LG005P)</i></p> <p><i>I know how the NHS works with research, and it's valid and it's always related to the patient, it's less airy-fairy I think [laughs]. Pharmaceuticals always reek of business and salesmanship. Universities, it's a case of students getting through, no disrespect to the students, but they are doing it because they have got to get through the other end, and sometimes, it's just, I don't know how valuable it is, other than them getting through an exam, I don't know if the end result has any value. But the NHS, yeah. It's how they are going to get ahead basically.(LG007P)</i></p> <p><i>I get loads of commercial contact and I just didn't want to be bothered anymore and also I think they would probably have their own axe to grind, they might not be an impartial as NHS, so yeah. (LG008P)</i></p> <p><i>Because of my views I'm a socialist, political, political really, I resent very much the sort of the drug companies, yeah the idea of private medicine really, because I think it should be something for everybody. (LG009P)</i></p> <p><i>I didn't want to be caught up in a load of promotional stuff thereafter... their motives might be less honourable... involving money and finance and selling stuff to people... I just think that sometimes industry doesn't do things for the best motive, and I fear that people's personal details could be, not used against them, but used in a way that doesn't suit me basically.( LG001P)</i></p>
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	<p>Social media Data issues Limiting sharing</p>	<p><i>I do do Facebook but it's the only one, I did have, when it all hit the fan, last year of whenever it was, I did Seriously considered closing down my account but there are one or two groups I belong to which I really didn't, one of them being the village page which keep me abreast of what is happening, and stuff that fuels my passion for photography and gardening and various things, so I didn't want to do it, but I did think about it.(LG001P)</i></p> <p><i>I do a little bit, I've got Facebook and Instagram, but only a little, I look at twitter as a news feed, I look at Instagram only because it's handy to share photos, I barely use Facebook, in fact I would cancel Facebook but I have a lot of family and friends on there, if they wanted to contact [me] it's an easy way to do it, I'm not a big social media user but I do use it to a limited extent. And that's probably more dangerous for social stuff. (LG002P)</i></p> <p><i>I call it anti-social media. It's responsible for a lot of the nasty things that are happening now. I have emails, I text, I phone, I know how to use a mobile phone, but no, none of my friends really get involved, some of my former colleagues do, because it's useful for professional reasons, Facebook, but otherwise no. (LG003P)</i></p> <p><i>I don't do Facebook, I text, and I've got me phone, I use me mobile phone quite a lot, I do use me ipad. (LG004P)</i></p> <p><i>I'm very limited to what I put on, Instagram, Facebook, WhatsApp, I mean I know these people who are hacking accounts are really really good at it, I mean the number of phishing emails I get, the last one was a TV licence rebate, no personalisation, Dear and then an email address, I think it was £258, just leave us with your bank details. I'm very wary now what I put on. I use a password manager called dash word and every password I have got is different, it's about 40 characters long, a mixture of numbers, letters and, so if I do get hacked they will have quite a long way to get to the password. (LG005P)</i></p> <p><i>...no, nothing... nothing, nothing at all (social media use). I've had me bank account wiped out on more than one occasion, me son has, in fact he just got a phone call off the fraud squad last week. Me mam's card has been cloned twice, so now no one of us use cash machines we go into the post office and when I've got me mobile I knock me Wi-Fi and data roaming off when I'm out and about, blue tooth. (LG006P)</i></p> <p><i>I have quite strong feelings about social media, I can see that is has value, and my [relative]who lives in</i></p>
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		<p>[European country], [they] got involved with it and has now engaged with a lot of [their] friends again, [they] were very solitary and [they] are now engaged with it again and for [them] it is valuable, but my grandchildren when they are threatening to go on, I think, it's such a dangerous place and there is so much inane stuff going on. It's dumbing down basically, I know the children are saying there's a lot of young people, acting very very silly irresponsible way which is geared up to be funny and it appeals to them and it's not doing them any good, you know. I just think it dumbs down. There are good parts but I don't buy stupid people. It has its place but not in my world. (LG007P)</p> <p>I also think its cruel, (social media) and its isn't always cruel because people mean it to be, but because you cannot see somebody it can come across and cold and cruel. (LG008P)</p> <p>I'm very against Facebook, some of my friends are for it and some are against it, I've got a friend in [city] a close friend and she is really annoyed that I won't do it. And lots of people have told, I do miss out on things cause I won't do it. I used to go to [place name] and it's a really strong group of people who pot, they all keep in touch with each other via Facebook so I miss out on that, but I obviously, it's my choice I feel a bit penalised because I don't do it, but I'm not prepared to do because something fundamentally is not good, and then you hear all these awful things. (LG009P)</p>
Progress	Digital communication Letters Face to face	<p>It makes me feel I want to say yes digital communication, I do think it's a generational thing if you are looking at getting as wider pool as possible and you want older people in there to, like me, they are more likely to want something on paper. I find physically reading a lot of information particularly in text form on my phone, which is tiny, laborious and I wouldn't be bothered. It's better on the lap top, but its better still on a piece of paper. (LG001P)</p> <p>Talking about receiving SMS reminders: No, not at all and especially if it's a reminder about an appointment, I don't think I'm going to forget anyway, hopefully but I'm quite happy to receive that reminder. (LG004P)</p> <p>I have used the appointment system, I had an appointment yesterday, you do have a backup text message through, it works quite seamless, the prescription side of it works well, it's electronic and I think in the modern day that's the way forward. You miss the human dialog, so I could say to the receptionist. It's (online account) good for looking at past prescriptions, there's some history trail to it, I think it's a work in progress to me honest, my own thoughts it that they could do more with it, it's early days. I do have an</p>



		<p><i>appointment about every six months, a review; it fits just what you have just said. Skype would be fine, how you feeling, they do take my blood pressure, which is a physical thing you can't do on skype. But yeah, yeah, I could imagine a lot of scenarios where people go and they do it on skype. So going back to your electronic record and appointment system, I think it could have information like that on, signpost, cause physically you are not going into the surgery so it would be another way of getting that information to people like myself. (LG005P)</i></p> <p><i>Not too digital please, the younger generation that is all they will know, but you have got to allow for the older people gradually phase it. (LG007P)</i></p>
<b>Themes from the staff interviews</b>		
Theme: Understanding of the research project.	Codes	Supporting text
	Volume and diversity Routes of communication Informed Resource	<p><i>The beginning part of an opportunity to recognise the volume of information we hold, in terms of patient numbers and that diversity of information we hold, recognising that the majority of research is carried out in secondary care and there is a huge untapped resource of information and everybody, all patients within primary care just making access to those patients and their information much easier. (LG001S)</i></p> <p><i>We want to make sure that patients are happy with how, they are happy with how we use their information, we want to maximise the ways that we communicate with them and them with us. (LG002S)</i></p>
Theme: Processes undertaken	Email problems SIP information Workload Royal mail Docmail Understanding and coding Delays Dynamic list	<p><i>Well the difficulty with email is that you don't know whether that account is active, you don't know if the account exists in the first place, because I think one of the 15 we looked at we thought one was a factious address, and we don't know whether those email addresses were solely used or used by the family. Email is not a particularly fashionable method of communication anyway these days and I think we had a conversation around they type of emails I get and very very few of them are for me about me, most of them are marketing rubbish so I think, email will not have any sort of longevity as a bona fide method of communication. (LG001S)</i></p> <p><i>(Email contact)...on the security, confidentiality, it doesn't exist, obviously within NHS.net and one or two</i></p>

		<p><i>other domains it's secure, but once it leaves that, it isn't secure at all. If I am asked to do so, (send an email to a patient) I always have that conversation with the patient around you understand what you are taking a risk I can't protect your information once I press send. I've never had anyone who's unhappy, I don't think they understand the risk, all be it very small, of it being intercepted, but there is risk obviously it isn't encrypted and it isn't protected end to end. (LG001S)</i></p> <p><i>Getting the language right has been very important, you remember when I first read this I didn't quite understand what the purpose of it was. My first take was, this was just an expression of interest, this isn't actually collecting and recording your preferences. So making sure the objective is clear. (LG001S)</i></p> <p><i>I think it would be beneficial to encourage the continued buy-in of the staff, just how many responses are coming in, what they look like, broad-brush, high level stuff. To keep everybody on board. (LG001S)</i></p> <p><i>I had to apply for a returns pre-paid returns licence. Probably took a couple of hours, understanding it and making an application, then the wait for the approval, then doing your art work, wait for approval for that. (LG001S)</i></p> <p><i>Interview 1 docmail: The address format, because for docmail to keep their costs down and ultimately the customer's costs down, they prefer everything to be in Royal Mail approved format, the addresses, so no extra lines, capitalisation that sort of thing, so of the 400 addresses I uploaded yesterday it said 249 were not formatted correctly. So it was then the case of understanding how docmail works, and their auto correction all those little bits and bobs behind the scenes, takes the time. So that was a faff, but once you get your head around what's acceptable that's fine. Then uploading the documents, that's also fine and straight forward, for the letter they are very prescriptive around where you have to have your blank space for where you have your space for where to print the patients name and address on, and the merge fields have to match exactly the merge fields on your spread sheet for where they are going to appear in the address and in your documentation as well. So you've got to make sure that everything is absolutely right before you press approve. (LG001S)</i></p> <p><i>Interview 3 docmail: it's a doddle it really is a doddle, same amount of work whether sending 10 or 10,000, essentially the same, if your addresses are consistent with Royal Mail expectations then it really is simple. You simply upload the file, you get a chance to check the quality of your addresses, and make suggested corrections and that is pretty much it, the only upload your letters or whatever other documents once and</i></p>
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		<p><i>you tell it you are sending this mail pack out to this number of people, and off you go, it really is simple. (LG001S)</i></p> <p><i>Actually try and get an understanding of the legislation, and the current rules and the current guidance, which is actually quite complicated, and even trying to understand what our current data flows are and how they are managed and how patients can control those data flows is really complex, and that's complex for somebody who has spent a lot of time looking at it, I cannot imagine what it's like for a patient looking who has never even thought about it, let alone someone who has a learning disability or dementia or whatever.(LG002S)</i></p> <p><i>There is the more specific bit which is about how do we record patients preference to be contacted about research so we built a system within SystemOne using some research codes so that we can record that, either a definite preference for yes, or a definite preference for no, for being contacted for research, from the three groups of institutions that are in the study. (LG002S)</i></p> <p><i>Other than experience of having been through it, not really, we were hampered by waiting for ethics to approve the change, we were hampered by Royal Mail, and I was hampered by docmail because I was a bit rusty using it, but if all those were in a row we would have knocked those over very quickly. (LG001S)</i></p> <p><i>The lack of having a dynamic patient list came to light mid-January on the second runs, and then, just to be aware that if this is to happen elsewhere, you need a means to record that these patients have had letters, then run your search again to identify who else is within the parameters, but excluding those you have already sent letters to. That gets more complicated, doable complicated, cause every time you do another batch you have to do all the searches again to identify all the patients. (LG001S)</i></p>
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<p>Theme: Drivers and Inhibitors</p>	<p>Drivers: efficiency and efficacy. Financial Communication</p> <p>Inhibitors: Nothing in it for me Interoperability Inertia Workload Issues with extending SMS services</p>	<p><i>I think there are a number of key areas, so, one of them is about efficiency, so making communication more effective, i.e. it actually works, it gets to the right place, if it's more acceptable to the patient then it is more likely to be effective, there is something about cost, we want to try to move to things that are cheaper like email and text, which are cheaper than old fashioned letters, things like traceability, so letters might go astray, I guess there is similar problems with email and text, but at least we've got different routes, so that, efficiency and efficacy of communication and there's also issues about new uses for communication and data use for things like research, dealing with patient concerns and professional concerns about how data is used and collected. (LG002S)</i></p> <p><i>I think possibly, people thinking there isn't anything in it for me, and, without recognising there isn't any potential benefit or gain years now the line. (LG001S)</i></p> <p><i>The fragmented nature of NHS digital has, the use of digitalised within the NHS is very fragmented. (LG001S)</i></p> <p><i>But then you have to look out for in 2020 what happens when the type 1 gets binned. But that's really complicated and how you expect patients to understand that, clinicians to understand that, in amongst everything else that they are trying to do I think it's really difficult. (LG002S)</i></p> <p><i>I think the bigger barrier is inertia and workload, rather than, you know I think the majority of people don't think, professionals and public, don't think very deeply about these issues at all, so the main issue, if you are thinking about the bits which are not contentious, about making things more efficient or effective I think the barrier to improving those bits are not legal or people worried about GDPR and all that, it's just the inertia of well we've always done it this way and changing it involves us having to think, whereas the bits about research, that is more about concerns about legislation and guidance. (LG002S)</i></p> <p><i>If they were also seeing the other benefits in terms of this is going to help with CQC or, the benefits as well as you are only doing this for research, cause you'll still get practices that say they're just too busy, we're not interested, we're not doing this for just, we don't have anything to do research, we don't have to do it. (LG002S)</i></p> <p><i>That is potentially a problem as well because with text you can only send very limited information, you cannot send rich information, you can't send hyperlinks, you don't know is somebody has a smart phone it might just be an old, a Nokia brick in which case a hyperlink is not going to work, so that does create some</i></p>
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<p>Outcomes and findings</p>	<p>Benefits Communication routes Commercialisation Response rate Single record</p>	<p><i>Rapid uptake, rapid uptake and access, to a willing cohort of patients. That's going to be the ultimate benefits of it. (LG001S)</i></p> <p><i>Efficacy and efficiency, so it's the things like, we would hope this would reduce your postage costs, we would hope this would reduce your staff time in folding envelopes and sealing letters, that sort of thing, franking machines, stamps or docmail costs, whatever it is that the practice uses. And then the effectiveness, you know, if you are communicating better with your patients then that should mean you don't have to contact them as often, you don't have as many complaints about miscommunication and so on. (LG002S)</i></p> <p>Interviewer: If email is not going to be a bona fide, if you are thinking of digital, to cut out the letter and the postage what do you think is going to be the bona fide method?: <i>LG001S: something, if you remember the MJOG app sort of thing, that people will subscribe to, not necessarily pay to a service, but that becomes your MO for communication.</i></p> <p><i>I don't know, I really don't because I think it might have a detrimental effect, if patients feel that we are encouraging them to take part in research and we are going to get some income from that, so maybe I think most people are more altruistic than that, for the benefit of the greater, rather than the individual or the practice. (LG001S)</i></p> <p><i>I think that having that information about text is really helpful, cause that is potentially really useful for practices just in terms of money saving, sending a text is free, sending letters is very expensive, and if that is a win win, if that is what patients want and it's better from our point of view. What would be interesting, a really interesting trial would be to randomise people, say for chronic disease reviews to text or letter to see</i></p>

		<p><i>if there is any difference in response rate. (LG002S)</i></p> <p><i>That brings us back nicely to what I said when I first came on board, if we had enough time to invest in the MJOG product for SMART phones we probably would have done that. Promoting the product, the use of the product and using it for the survey. (LG001S)</i></p> <p><i>You need to keep it (permissions choices) in the patients record as far as possible, not an independent database. LG002S is trying to develop read codes so therefore, it will follow, the patient will leave us and it will go to another practice, that consent or pre-consent stays with the patient and not in a standalone database. I'm a firm believer in one patient should have one entire record. (LG001S)</i></p> <p><i>I guess my concern about the whole research bit is that we don't make things too complex for patients, so we are not going to them and asking them for loads of different systems, and saying, but would you like to opt into this system and then would you like to opt into this system, ideally we want a single, kind of, patients to only really be contacted once for general purposes, obviously for specific issues we might go to them as many times for different projects, what we don't want is lots of different opt in systems, general opt in systems. (LG002S)</i></p> <p><i>Well I guess the people who want communication by post, communicating with them digitally isn't going to be more effective anyway, I think as long as you don't go down the route of saying if we had some sort of initiative, research initiative or direct health care initiative as long as you're [not] saying we can only deliver that to people who have got a digital channel then I don't think there is a major risk of alienating those people, as long as you are saying that now we have a health initiative let's say we are going to target people for a flu vaccine, we are going to email and text, as long as you are making equal effort to contact the people who don't have those digital channels by telephone or letter then I think that's a reasonable approach. (LG002S)</i></p> <p>Response rate:</p>
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		<p><i>That's very high, much higher than I was expecting...may be 10 [%] if we were lucky. I don't know whether the idea of being able to express your preference for how you want to be contacted is quite a draw for patients cause that actually does make a difference for basically management and ease of their, even if they are not interested in research at all, I wonder if that was helpful. Or just that they like us. (LG002S)</i></p> <p><i>That's way in excess of what I imagined it to be. I thought it would be in single figures to be honest. The reasons why I thought it would be single figures...[yeah]...just I didn't think, you know I voiced concerns at the very onset when I first joined the project that it wasn't very clear to me what it was all about. And then the information about sharing data and all that stuff became a little bit too cold and not particularly user friendly to read. So I thought those things would perhaps preclude some people from responding. I'm pleasantly surprised it hasn't. (LG001S)</i></p> <p><i>I think possibly they don't understand what that means and it's just a blanket 'this sounds a bit scary' and the easiest thing is just to say no, and that's fair enough.(LG002S)</i></p> <p><i>And also the whole concept of consent to data is kind of a bit out of their radar, it's just 'I give it to Facebook and they can have it', they are not even that bothered. Agree agree, agree, which has got even worse since GDPR came in, because everything now asks you, I'm guilty of it, just agree, agree. (Poor response rate from 18-29 yrs. group) (LG002S)</i></p> <p><i>That increasing age will come in line with increasing exposure to long term conditions and so on, possibly answer why some of the young just didn't (respond). (LG001S)</i></p> <p><i>A significant percentage of those who completed the online survey also completed our own GP survey as well that's not related to this project, I forgot to mention this to you actually, so the friends and family test, it's whether you would highly recommend, or partly or not your practice. So the majority of those filled in were very positive about the practice so actually it's this discussion about the affinity patients feels towards their practice I think that had a part to play in it. (LG001S)</i></p>
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