

Electronic Shared Care Record

Public Engagement Activity : October and November 2016

Purpose

This research was focussed primarily on determining the acceptability of an electronic shared care record among the people of Bolton.

- **This information should serve to clarify broad public opinion on the concept of shared care records (as opposed to other kinds of electronic data sharing)**

The research also sought to establish where the locus of any concerns might lie, both in terms of demographics and in terms of issues.

- **This knowledge will enable the health and social care system to focus its efforts in terms of further engagement and information.**

Method

A straight survey method was used in order to;

- Reach a broad spectrum of people
- Provide clear answers on the question of acceptability
- Allow responses to be cross referenced with demographics

The survey was available on-line and in paper format, and was distributed as follows:

- At a variety of events and activities organised by the voluntary sector and attended by CVS or Healthwatch
- Alongside other engagement activities such as those that take place on the corridor of the Royal Bolton Hospital and in GP Practices.
- At the CVS Hub building reception
- The electronic link was circulated via both the Healthwatch Bolton and CVS database, tweeted and added to the websites and Facebook pages of both organisations.

Where face-to-face methods were used, an information sheet (provided by Bolton CCG) was used to support people to understand the concept of the Bolton shared care record.

Four Questions

- Question 1 :
‘What do you think of The Bolton Care Record?’
Five statements with options to: strongly agree, agree, neither agree nor disagree, disagree or strongly disagree.
- Questions 2-4 opportunity to provide individual (free-written) feedback on the following;
‘What do you think the benefits might be of having a Bolton Care Record?’
‘Let us know if you have any concerns about the Bolton Care Record?’
‘Please tell us your suggestions on how we could improve the proposed model for a Bolton Care Record.’
- Plus Demographic data questions on post code, age, gender, sexuality, ethnic background, religion, employment status, disability status, carer status.

Respondents

146 Individuals :

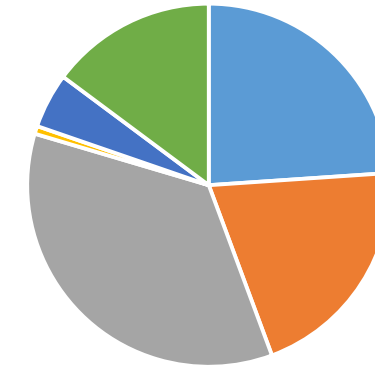
47 male (33%) : 81 female (56%) : 1 other (1%) : 17 not declared (10%)

41% (58 people) described themselves as disabled

27% (38 people) described themselves as carers

6 % (8 people) described themselves as LGBT

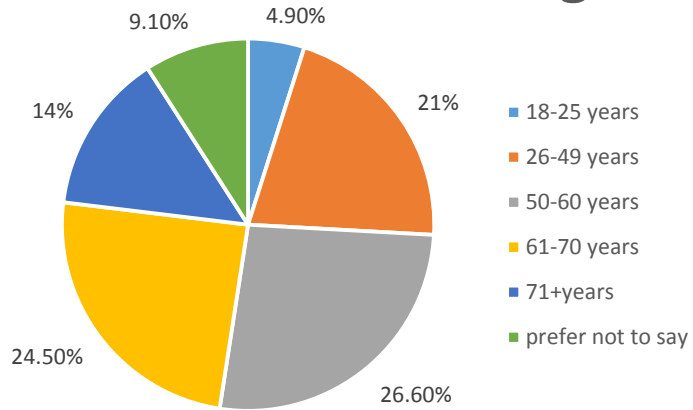
Employment Status



- Employed (23.9%)
- Unemployed (20.4%)
- Retired (35.2%)
- In education/training (0.7%)
- Other (4.9%)
- Prefer not to say (14.8%)

4 people skipped this question

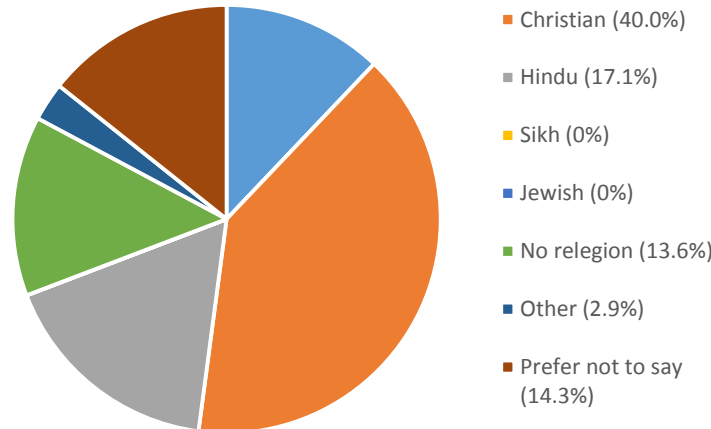
Age



- 18-25 years
- 26-49 years
- 50-60 years
- 61-70 years
- 71+years
- prefer not to say

3 people skipped this question

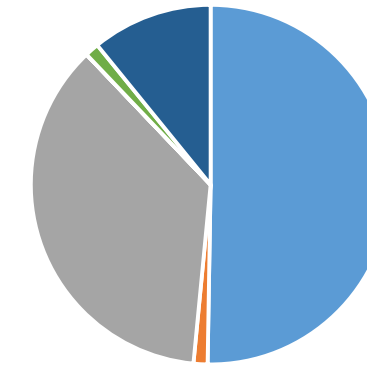
Religion



- Muslim (12.1%)
- Christian (40.0%)
- Hindu (17.1%)
- Sikh (0%)
- Jewish (0%)
- No religion (13.6%)
- Other (2.9%)
- Prefer not to say (14.3%)

6 people skipped this question

Ethnic Background



- White British (56%)
- White other (1.4%)
- any Asian/Asian British (40.5%)
- any Black/Black British (0%)
- Chinese (0%)
- any Mixed (0%)
- Prefer not to say (12.1%)

5 people skipped this question



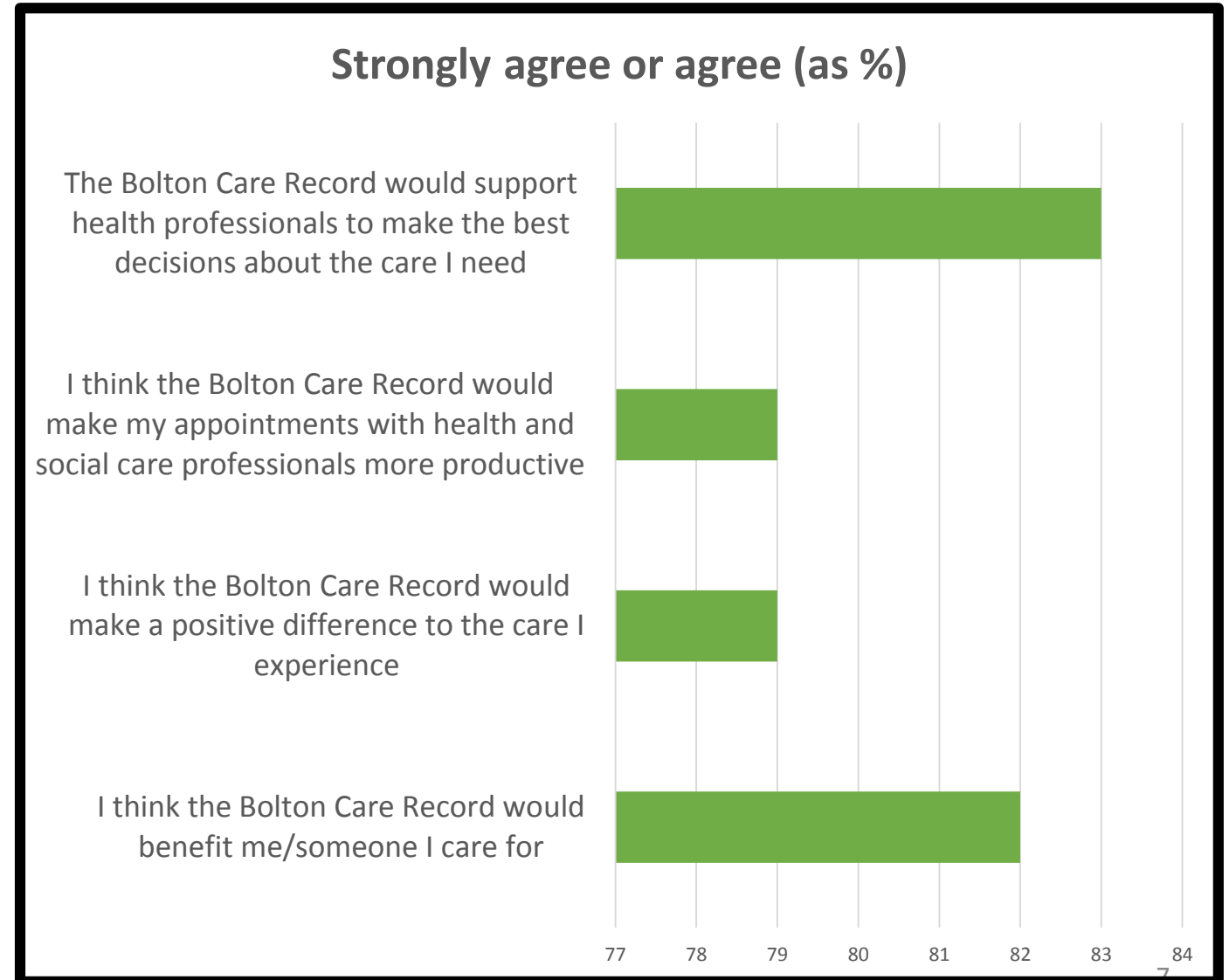
I see the benefits

Question 1 : ‘What do you think of the Bolton Care Record?’

Do people see the benefits of a Shared Care Record ?

Overwhelmingly , Yes.

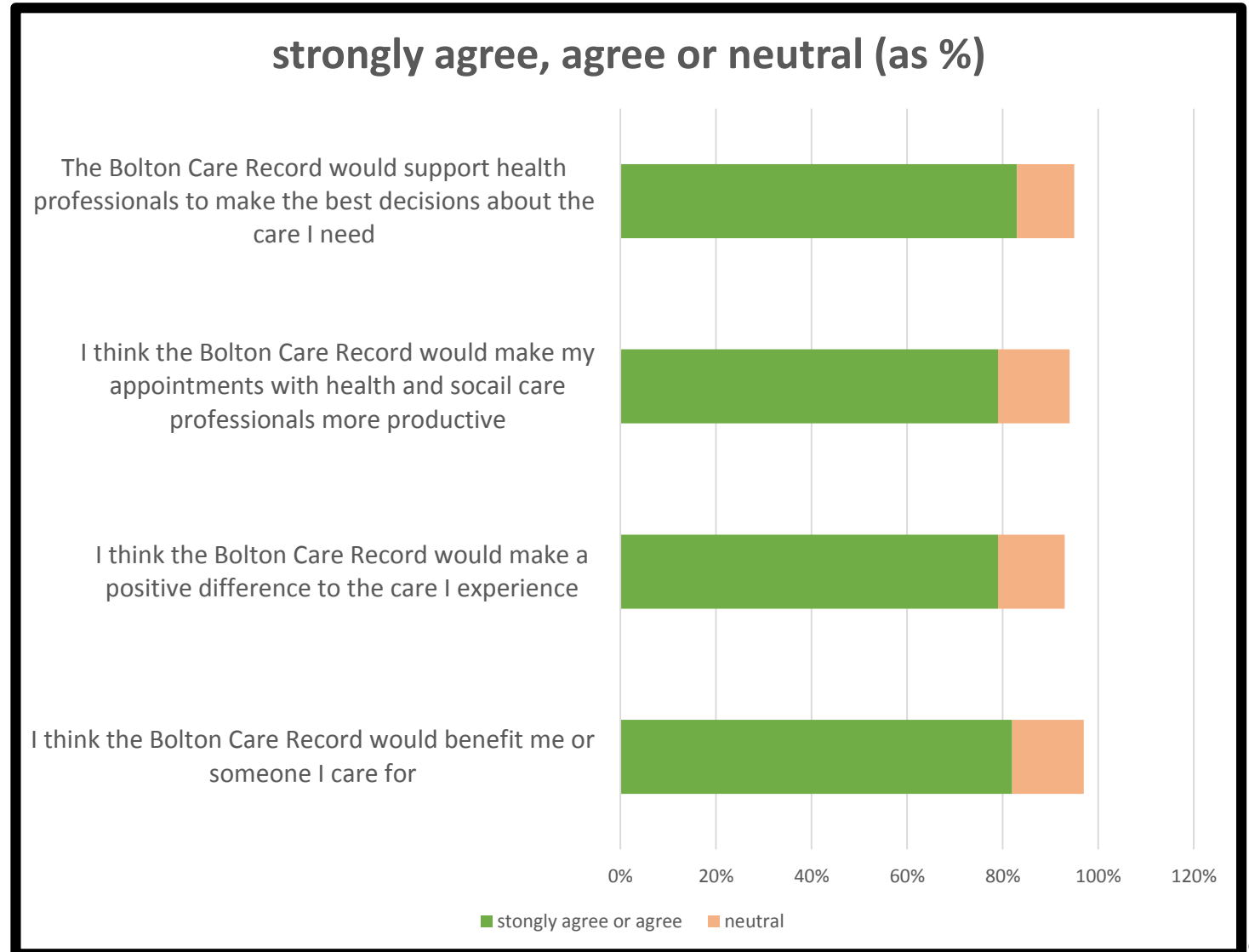
Between **79%** and **83%** of respondents either ***agreed*** or ***strongly agreed*** with all four statements describing positive benefits.



Question 1 : 'What do you think of the Bolton Care Record?'

If we include those who gave a neutral answer (*neither agree nor disagree*).

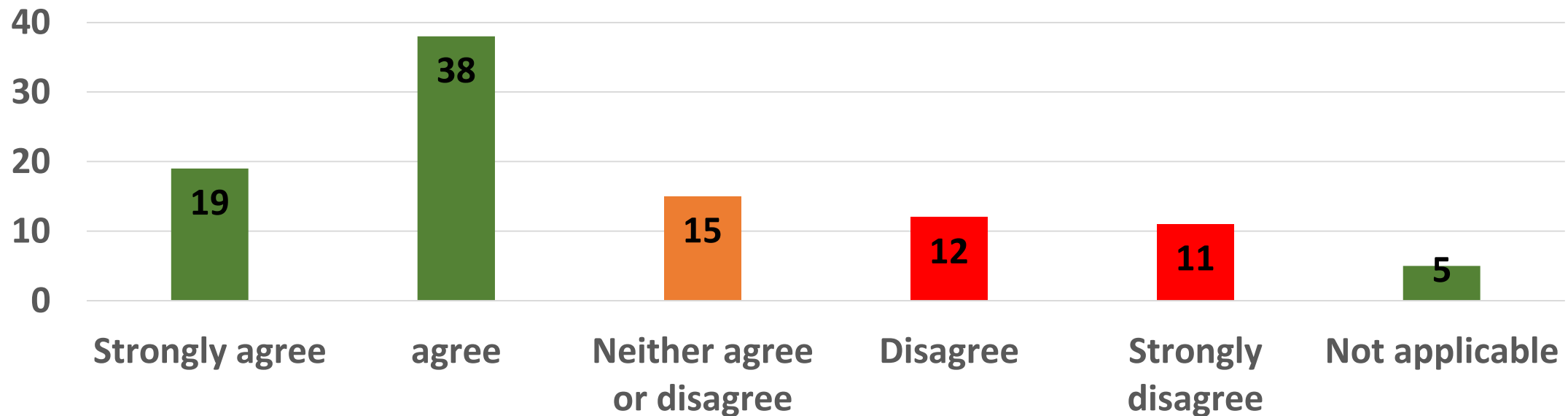
Those respondents who are either positive or ambivalent towards the positive benefits rise to between **89%** and **92%**.



Question 1 : 'What do you think of the Bolton Care Record?'

It is interesting to note that **57%** of respondents thought the care record was *already shared* among health professionals.

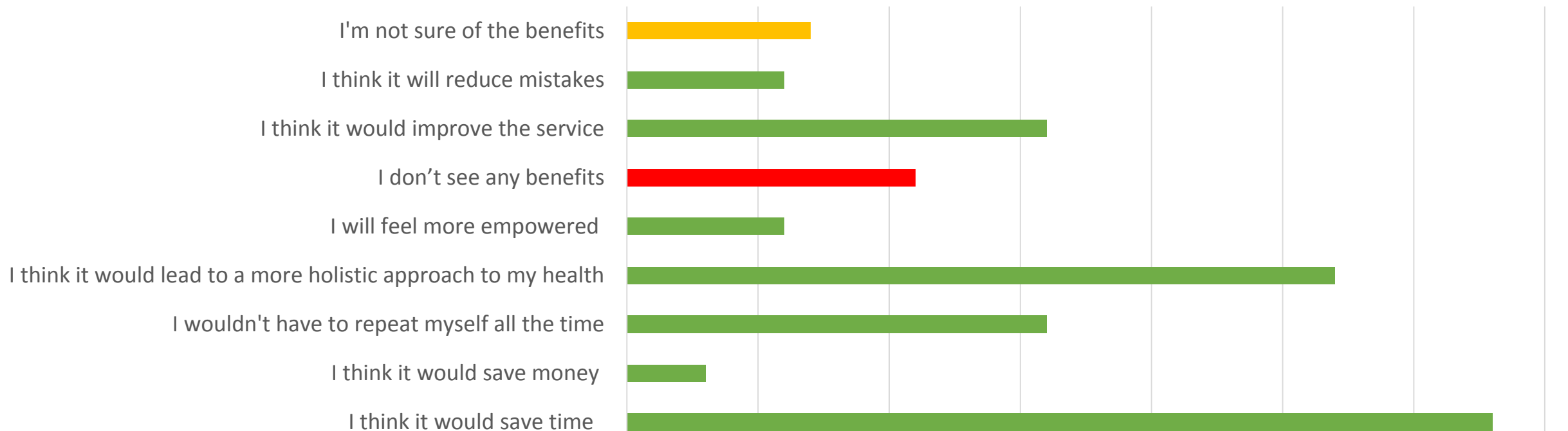
I thought the information from my health record was already shared among health professionals (in % n=145)



Question 2 : *‘What do you think the benefits might be with having a Bolton Care Record?’*

There were 125 responses to this question which have been grouped against I-statements for the purpose of analysis.

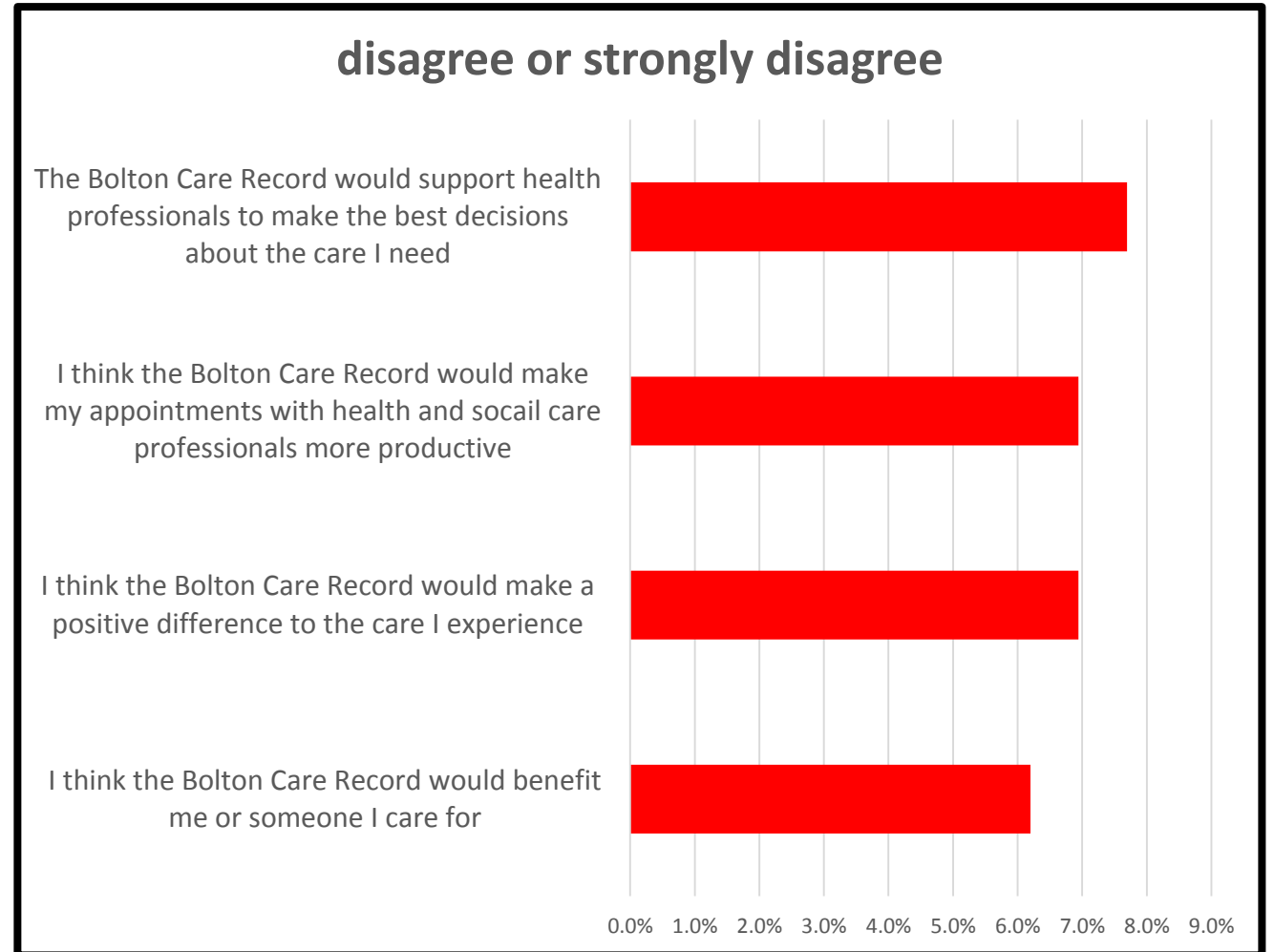
Comment count: I statements



Question 1 : *'What do you think of the Bolton Care Record?'*

Between 1% and 6% of respondents thought the statements not applicable to them.

This leaves **6.2%** and **7.7%** who **disagreed or strongly disagreed**.



- *Access to enable professionals to get me the care I need quickly*
- *Quicker access to information and therefore quicker help*
- *Saving time*
- *Save time at each appointment and hospital admission*
- *Streamlined services, save time.*
- *Streamlined care (i.e.; between mental & physical/NHS services)*
- *More efficient - no delays accessing records*
- *When you need help and support the professionals can look up your history*
- *It is a good idea because maybe treatment can be dealt with quicker.*
- *Save time & effort*
- *Information sharing quickly*
- *You would have quicker access to health records*
- *If taken to hospital or a clinic, my records would show what medicine I am on and the treatment would start straightaway*
- *Easily accessible - know my history*
- *Easy and quick access for Health and Social care professionals and to make the best decisions about my health.*
- *Faster, more informed decisions about understanding health care.*
- *No time delay in case of emergency.*
- *Will have better treatment, professionals will have more time to treat people.*
- *Time saving - reassurance people are listening and know you (about you)*
- *Easily accessible records in case of illness/hospitalisation*
- *Quick care*
- *No matter who treats me, they can see the right information. Saves time*
- *Saving time*
- *Easy and quick access when needed*
- *Professionals will be able to spend more time with patients*
- *Save me and professional time at appointments*

I think it will help to speed things up and save time

...and money

Better services - efficiency - cost effective

- *Cut costs*

- *Would not have to keep repeating yourself. e.g. meds - (view a screen) can't remember everything and what they are called.*
- *We can have better treatment then I don't need to take all my medicines to appointments at hospitals*
- *It reduces stress in having to repeat health history to many health providers*
- *Not having to repeat information - eg. Complex conditions, end of life eg. D.N.R*
- *Not having to repeat your record at every appointment.*
- *Medical information available*
- *It would be helpful as I won't be having to explain.*
- *No repeating every time.*



- *Professionals would have history and save me explaining previous health issues.*
- *Then I don't have to keep repeating my health info.*
- *Would prevent me trying to remember and be able to get it straight away.*

- *I recently attended an appointment with my GP who was unaware of the medications I was on, because they were prescribed from the hospital. The GP was rude, dismissive and unhelpful as I couldn't name the three medications in the consultation.*
- *Integrated. Smoother - can see what meds your on for eg. I'm on Tramadol and have to explain all the time.*
- *Personally, it would be of benefit to me as I have allergies and would want health professionals to know when treating me. Consistent health care & no need to repeat myself.*
- *Not having to relay/remember all past treatment medication etc. Details of allergies etc. made available*
- *not having to explain yourself at every appointment*

- *Shared information between Health Professionals*
- *Helps services work better together. Potentially reducing hospital stays so you can get home sooner.*
- *Integrated health and care*

It will help people to work TOGETHER

...and so make better decisions

*My information would be more accessible to professional caring for me.
Correlate results between GP/ Clinics/ Hospital*

- *Enable services to take a more holistic approach.*
- *good for professionals to know my medical history*
- *It would be a lot easier to get to the root of a problem if everything is already there*
- *Other professionals can talk more about the care I need*
- *Individuals/professionals allowed to share experiences.*
- *We would like to help health professionals to do more than diagnose our illness*
- *They will know about all health problems, issues. Can talk to others involved in care to make some more effective in terms of care quality and cost*
- *More help with medical needs*
- *Maybe help with care I receive*
- *To provide integrated care*
- *All providers responsible for supporting an individual would have access to all relevant information to best support the person.*
- *Better quality of care, other professional would have a good understanding of my health issues I have.*
- *I would know that you should be able to understand me properly.*
- *Cross Department*
- *Holistic, integrated care*
- *They will have more ideas about our health*
- *More togetherness*
- *It allows joined up thinking*
- *Professionals will be able to make better decisions on my health.*
- *To help people like me and others*

**I think it will
reduce mistakes**

- *Information easily available, presumably in a concise form, would reduce the changes of unfamiliar health professionals missing significant details*
- *Complete record at each health appointment*
- *Easy accessibility for hospital or health care staff to correct treatment and diagnosis of patient*
- *Less mistakes with diagnosis by hospitals or other G.Ps*
- *Correct medication to go with what I already take*
- *No information would be missed*

**I will feel
more
empowered**

- *it will show me all my health records*
- *I can view about my health record maybe which I was not aware of because of verbal understanding*
- *Clients would feel safe and secure about the information*
- *We are so fortunate to have a democracy where peoples concerns are listened to and acted on*

**I think it's a
good idea**

- *I would suspect that sharing medical records would have a lot of benefits*
- *Yes, really a good idea*
- *I think it could help me and a lot of other people*
- *Would be beneficial for NHS visits*
- *Helpful*
- *better service - more coordinated.*
- *If applied properly would be good*
- *Better joined up health care*
- *Get better treatment*



**I don't see
any benefits**

- *None. I am extremely worried about security*
- *the only benefit is to the private companies who will run services and insurance companies*
- *it's a fiasco - a done deal CCG and NHS England has already decided and its lip service - sell off!*
- *I don't agree*
- *Is wading through my records quicker than asking me.?*
- *Not much*
- *There is nothing to stop each person creating their own summary of their information*
- *None what so ever. Professionals sharing false, damaging information without my knowledge or consent has completely ruined my life*
- *None*
- *Small in comparison to the risk of disclosure to "wrong" people I would want to know just who has accessed this information*
- *Communication is already poor and if staff already do not lead or acknowledge allergies on a paper record will they take note because its on a screen within the same department from one member to another. Security of system.*

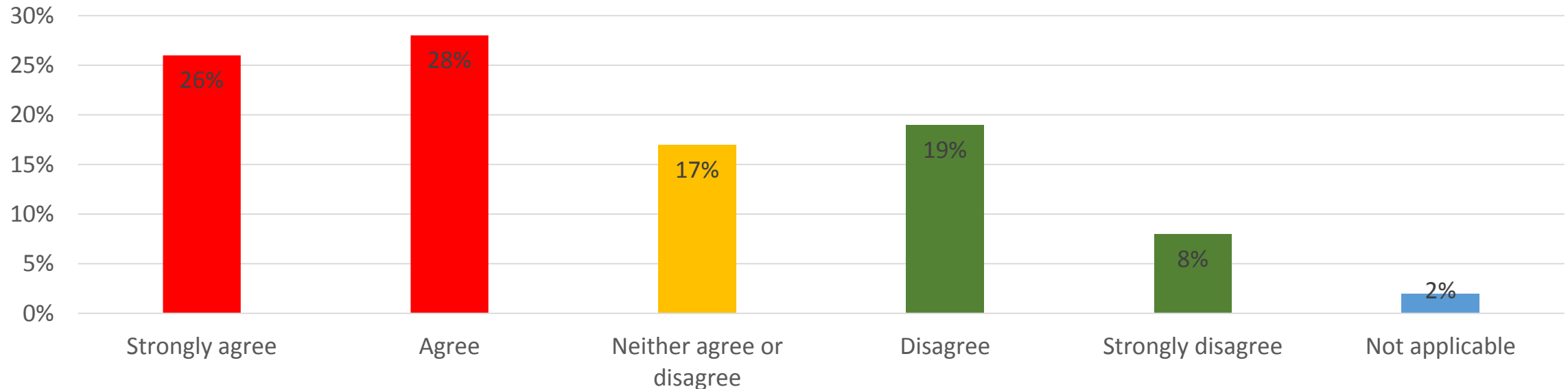


**I have some
concerns**

Question 1 : *‘What do you think of the Bolton Care Record?’*

56% of respondents *agreed or strongly agreed* with the statement that sharing information *across health and social care* was of concern to them.

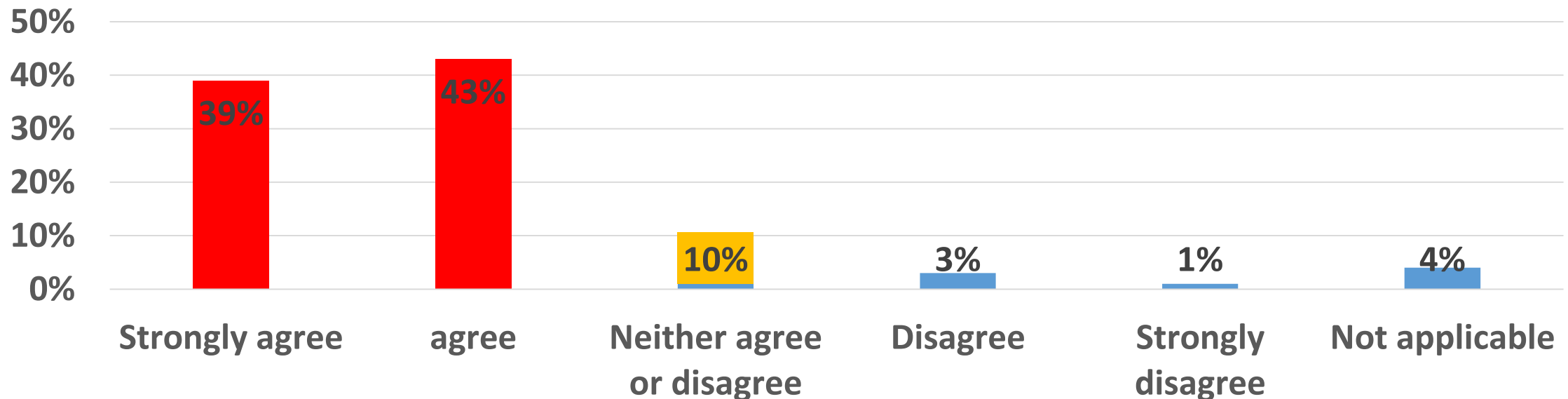
The sharing of information from my health records across health and social care professionals is of concern to me (n=145)



Question 1 : 'What do you think of the Bolton Care Record?'

82% of respondents ***agreed or strongly agreed*** with the statement they would want to know which health and care professionals would have access to the record, a further **10 %** were ***neutral*** on this point.

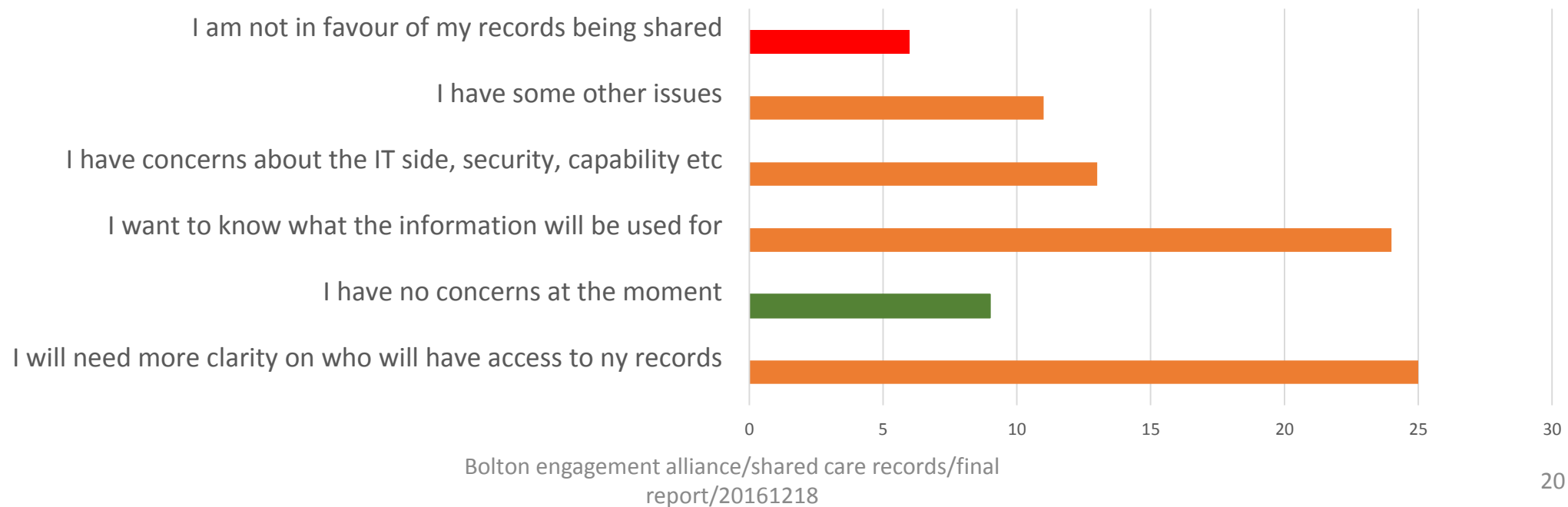
I would want to know which health and social care professionals would have access to the record (in% n=140)



Question 3: *'Please let us know if you have any concerns about the Bolton Care Record'*

There were 74 responses to this question which have been grouped against I-statements for the purpose of analysis.

Comment count : I statements



I do as I don't know who would see it

Who will have access to my records?

Who has access?

Need to be kept within health only! Free from any others

So long as it's secure and used by professionals.

Who has access? Staff training required on accessing

Yes who could access my info?

**I will need more clarity
on who will have access
to my records**

Worried about who would be able to see my record

Who would be able to access personal information and how easily accessible would it be?

The wrong person gaining access. I would not want district nurse, social workers etc., gaining access and discussing my medical history with Mr World and his wife.

Only used by public sector, non statutory not for profit, sector needs to be involved

*Important to link with Salford, Wigan and Christie
Seems to be 'one size fits all'*

The only concern is what if my records go into the wrong hands.?

Only that professionals know how to use it and would use it properly

Inappropriate people accessing my data

**I need to know how
confidentiality will be
protected**

*However that would obviously have to be very clear
guidelines and information given regarding the
safeguarding and privacy issues*

*Who can and shouldn't see and that records are only
viewed at the time of appointment*

Confidentiality

Confidentiality

Will this be confidential?

When one visits a doctor, confidentiality is expected

Different access

I would want security levels

Privacy.

*Only concerned about who can access it and when.
Confidentiality.*

*I have concerns that my info does not pass on to
others. Other than people who need it*

**I want to know
what the
information will
be used for**

Shared with private providers i.e. insurance companies - potential employers (private organisations)

*Records being lost or accessible outside healthcare.
My personal information in public domain.*

People who don't need info (care workers etc) being able to access it

Information provided to private agencies

I have a concern about misuse

Consent - would need to be explained and provided in writing

Worry would be if information got into the "wrong" hands


As long as they are not misused

How far information goes

A little bit about the privacy side to do things

Once it's shown, where will it end in the future

*Too open to future government amending laws so that various ministers have access without your consent.
Information once public cannot be brought back.*



I have some concerns about the IT side, security, capability etc.

Needs extremely robust safeguards What if system crashes?

Will the I.T. System cope? Universal credit had been delayed over and over because the I.T. isn't working.

will all technology work together? i.e. talk to each other

Data being hacked.

Security

Hacking

I think for security every time the records are accessed the patient gets some sort of alert. By who, where and when. This should be recorded in an indestructible way.

Not as long as security measures are adequate

Security - external provider - not all NHS using same systems don't talk to each other

- *Not really*
- *If it is done properly and legally should be no worries*
- *I think it will be beneficial to all concerned*
- *Not at present unless it's used wrongly by medical professional*
- *Not really - "They are helping us"*
- *Positives outweigh the negatives*
- *I don't have any as of yet*
- *I have none at the moment*

I have no concerns

- *Sharing of information has resulted in bad experience for me*
- *I am currently going through an extremely serious complaint against (a health provider) regarding the appallingly inaccurate , false and damaging information they have. ... damage (has been caused).... Thanks to 'professionals' sharing information without my knowledge or consent*
- *I don't like the idea of my information being accessed across the town*

I do not agree with the Bolton Care Record

- *I don't want people to look at my private information*
- *I disagree with all organisations having access to my records.*
- *Don't like to give Bolton Care Record without my permission*
- *I would like to tell professionals myself what I feel I want them to know.*



I suggest

Question 4:

‘Please tell us your suggestions on how we could improve the proposed model for a Bolton Care Record’

55 suggestions were made in response to this question.

Suggestions : I statements



I would like to see more information, engagement and consultation on this matter

- *More awareness More education on this matter*
- *Carry on asking patients as each step/decision is made*
- *Consultation with as many social groups to meet concerns as possible*
- *More information for the Mental Health organisations in the Bolton area.*
- *Let more people know of the service*
- *More consultation with different groups, eg. doctors patient group*
- *Not seen or heard of it till now*
- *Proper consultation*
- *Help training, flexibility, awareness of conditions*
- *More information of how this would work*
- *Work with Healthwatch Bolton - Make clear how SSD will act within this system*
- *don't fully understand it*
- *Needs more information*

I would also like my information to be accessible to me

- *Can people request what is available*
- *I would also like to access my info.*
- *Make it across the board accessible*
- *think that the patient should be able to view and amend the record also, giving the person who the information is about some ownership. Even if for starters, it is just viewable information, it is my information so I should be able to access it too.*
- *Include communication needs of patients - I'm Deaf and a lot of communication is by telephone only.*
- *Make it accessible to read for patient.*
- *Make sure everyone who wants a care record has one*

I would want to see a clear process for informed consent and opt out

- *(Be) very, very careful informed consent*
- *(I would like a) meeting with all professionals information would be shared with*
- *By communication with individual*
- *By telling the individual of their concerns*
- *Get permission of patient every time, allowing a person to give consent to a particular health provider and any others consent*

I would like some more guarantees

- *sounds ok - may need to put safeguards to ensure eg. that medication is deleted if changed and records are up to date*
- *Even if the health records do have password, it still gets forgotten leaked, so at this moment I'm not sure if I am the right person to acknowledge about improvement. Maybe an app might be useful for smartphone suggesting which professionals went through my records only with my permission.*
- *Provide each person with a chip/card with a key summary rather than all detail*
- *Password it only for medical use Dr – Patients*

I think other people should be involved

- *Include pharmacist*
- *Involve other sectors, egg education(for young people) and care / nursing homes*
- *Involve all, i.e. 'family' and 'person receiving care'*
- *To allow access across the country*

I have some technical suggestions

- *Password it only for medical use Dr – Patients*
- *Provide each person with a chip/card with a key summary rather than all detail. Even if the health records do have password, it still gets forgotten leaked, so at this moment I'm not sure if I am the right person to acknowledge about improvement. Maybe an app might be useful for smartphone suggesting which professionals went through my records only with my permission*
- *sounds ok - may need to put safeguards to ensure egg that medication is deleted if changed and records are up to date*

I think it sounds like a good idea – get on with it!

- *Sounds good as it is*
- *Make it better. People (some) seem to find fault with everything. I am grateful.*
- *Looks okay already.*
- *To access it so that treatment can be done quickly*
- *Just to make it better and quicker*
- *Good*

I think it should be scrapped

- *Scrap it?*
- *I am completely against it*

CONCLUSIONS

Conclusions

There is a very high level of acceptability amongst the general public for the concept of an electronic shared care record (at around **80% positive and 90% either positive or neutral**).

It is also worth noting that **57%** of people thought that records were **already** shared among health professionals.

- The most commonly cited benefit it is saving time (for patients, for professionals and within the system – eg. by reducing the length of time between referrals and appointments and between tests and results, for example).
- A small number of respondents equated these time savings to increased efficiency and cost saving.
- The second most commonly cited benefit was making the system more holistic by supporting professionals to have a rounded view of an individuals health status and wider circumstances.

Other benefits cited included;

- Not having to remember/repeat information to every professional (which would also be time saving)
- Individuals feeling more empowered (if they can see the record for themselves)
- A reduction in errors / mistakes.

Conclusions

The high acceptability results do not, however, mean that there are no concerns.

54% of people agreed that they had concerns about sharing information between health and social care professionals and, in the same vein, the majority of respondents (82%) agreed that they would want to know which professionals would have access to the record.

This chimes with the results of the I-statement counts which show that 49 respondents (66% of relevant statements) who elaborated having concerns about the proposal wanting to know;

- WHO would have access to the record,
- WHAT the information would be used for
- HOW confidentiality would be preserved.

Other concerns raised included some about the capability, security and ownership of IT based systems.

Conclusions

A small number of people consistently expressed serious concerns about a shared care record.

These individuals had nothing specifically demographic in common but would seem to share some common experiences or traits.

There were issues which could be described as related to 'Privacy'

There were some issues which could be described as related to 'control'

There were issues described which can be correlated to previous bad experiences of either health and care or specifically to the sharing of health and social care information.

Conclusions

It would seem that there is a relationship between confidentiality and professionalism and professionalism and access to the record being acceptable to the public.

If people who are seen to understand confidentiality in a professional context can view the record that's ok, but what about receptionists, care workers etc.? Does the public believe that these people appreciate and respect confidentiality?

If the condition of confidentiality is guaranteed (which is considered done under the heading of professionalism) then shared access is seen as an overall benefit.

Conclusions

- People requested:
 - More information and consultation on this subject
 - Clarity around who will have access to the record
 - Some guarantees
 - A clear process for gaining consent and opting out
 - To be able to access the record themselves

RECOMMENDATIONS

Recommendations

- General information channels should be employed to inform more people about the shared care record.
- Information should concentrate on the benefits suggested by the public (time saving, holistic system, less repeating oneself, patient safety).
- There is a (minority) appetite for more technical information so the technical aspects of the proposal should also be put into the public domain (packages, suppliers, security record of suppliers, mechanisms for activating permissions, technical approach regarding patient access)
- Options proposals should be worked up on;
 - Which (specific) professionals might have access to the record
 - Possible processes for opting in/out

Recommendations

- **Some case studies should be co-produced with members of the public who have;**
 - Had bad experiences (people who have made complaints)
 - Have supported people in end of life care
 - Are in receipt of complex health and social care packages
 - Have experienced trauma care
 - Have severe and enduring mental health problems and physical health problems
- **Using these case studies as prompts, a second round of engagement should take place questioning people on;**
 - Which specific professionals should have access to the record and under what circumstances
 - Which processes for opting in/out are most desirable /acceptable

THANKS TO EVERYONE WHO PARTICIPATED IN THIS ENGAGEMENT ACTIVITY

Bolton Engagement Alliance/Healthwatch Bolton/Bolton CVS December 2016