

GNCR-Network Event (July 2018) Report

Shaping the Great North Care Record (GNCR) approach to privacy preferences: practitioner perspectives

Author: Dr Michaela Fay



What is the Great North Care Record?

The Great North Care Record (GNCR) is a new way of sharing medical information across the North East and North Cumbria, which is accessed by health and social care practitioners to provide direct care for patients. It means that key information such as diagnoses, medications, details of hospitals admissions and treatments can be shared between different healthcare services.

The GNCR explores opening up healthcare data to more groups such as social care providers, healthcare planners, public health teams, and researchers.

Healthcare records are a rich, but untapped source of information, which, in the hands of researchers, could bring new insight and discoveries about treatments and diseases. This has not been achieved on a large scale before, as obtaining permission from the public to use their information in this way is difficult. The Great North Care Record seeks to overcome this challenge.

Preference Setting

The setting of information sharing preferences within the GNCR, allows members of the public to specify what they want their health and social care information to be shared for. This includes sharing information for research by the GNCR; for care; for research purposes; or not at all.

Preference setting is not the same as a patient's consent to receive care, for example. It is about making an informed and active choice about how, when, and with whom particular aspects of their health and social care information should be shared and for what purposes.

Engaging frontline staff/health care practitioners

Engaging health care practitioners, service developers and frontline staff in the development of the GNCR and its associated preference setting tools is an important element to making sure it is a safe and useful tool for both patients and health practitioners. Ideally, patient preference setting allows frontline staff to easily and quickly share and access the most relevant patient information at the time it is needed in order to provide seamless and targeted care and develop and design services with seamless and targeted care in mind. Furthermore, patient preference setting should enable trusted clinical and academic researchers to easily access large quantities of research-relevant health data.

Why is practitioner engagement important to the GNCR?

The GNCR is co-produced and co-designed with citizens and practitioners. Practitioners' buy-in and full grasp of the underlying principles and application in practice are essential not only to gain citizens' buy-in but also to ensure health practitioners, service providers and planners work towards a shared goal.

The Great North Care Record Network

The Great North Care Record Network has been established to support the development of the Great North Care Record across the North East and North Cumbria.

The Network provides an opportunity for professionals working in healthcare, social care and academia to come together and to help implement the record across the region.

The programme has been established and is led by local health and social care professionals and academics, who are committed to the benefits of better information sharing, in a safe and secure setting.

The network meets on a face to face basis and has an online network – Discourse.

Network Event – Professional insights and engagement

The GNCR Network Event

The networking event in July 2018 was targeted at health and care professionals and academics. Approximately 350 participants attended to discuss how permission can best be captured from 3.6million people across the region to share (or not share) their health and social care information for direct care, research and planning.

People working across the health and care sector were invited to attend. This included clinicians from acute, primary care, community, local authorities, IT professionals working in the service and representatives from patient groups and voluntary organisations.

Alongside a conference-style element consisting of stakeholder presentations from a variety of speakers, the event offered a workshop element. This component of the event allowed practitioners to work together and brainstorm ideas. These were then captured and analysed according to the *ECOUTER* method.

The workshop design was inspired by the *ECOUTER* method developed by Professor Madeleine Murtagh and team at Newcastle & Bristol universities.

Participants' ideas and concerns around health information sharing were captured on 'sticky notes', which, after then event, were then collated into a spread sheet by Corinne Anderson and analysed for themes by Dr Michaela Fay.

Participants' feedback was collected with the two-fold aim to

- Enable networking across different practitioner groups and
- Inform the next iteration of the Healthcall/Inhealthcare model and to learn more about the legal, social, and technical aspects of information sharing

requirements, specifically in relation to preferences, confidentiality, and consent.

Specifically, participants were asked two things:

- 1) To reflect on what capturing permission for sharing health and social care information would mean for them (in their respective professional roles) with regards to direct care; service planning, and research issues.
- 2) To describe what, from their perspective, would be needed to make citizen-led preference setting work successfully and sustainably in their role or organisation.

A number of common themes were identified:

- 1) There is a need for “a common approach” and a “clear strategy that everyone is signed up to”
- 2) There exists a lack of “true interconnected [IT] systems”, making the sharing of patient information difficult, in particular with regards to direct care.
- 3) In order to get both the healthcare profession and the public to buy into the idea to routinely and actively share their health information, “a marked change from often patristic professional decision making to one that embraces patient knowledge” is required. This extends to “a cultural shift that includes the patient taking responsibility to make their voice heard”
- 4) Effective communication strategies are required to “Increase public awareness” of the benefits of and the need for more integrated and comprehensive information sharing
- 5) Digital end user platforms need to be made available that provide the necessary “granularity” of what is shared, with whom, and for what purpose.
- 6) In order to build and maintain trust in a culture of information sharing, assurances have to be cultivated “that patient information is as secure as possible and not used for commercial profit”.
- 7) Sustainability of an information sharing culture requires “Transparency of how patient data is being used. This includes the distinction between uses for care and uses for research”.

The ECOUTER Method¹

The *ECOUTER* methodology for stakeholder engagement aims to open up discourse and facilitate conversation to capture a range of perspectives while assuming none to be privileged. It is not a ‘consensus’ method so does not seek a final or fixed answer. Rather, it is part of a process where questions are posed to excite and elicit responses.

¹ (Murtagh et. al., 2017, <https://doi.org/10.1186/s12910-017-0167-z>)

Broadly speaking, there are four steps to the *ECOUTER* methods:

1. Engagement and knowledge exchange ('mind mapping')
2. Analysis/synthesis
3. Conceptual framework/recommendation development
4. Feedback and refinement

Summary of Findings

Summary of Themes:

- Stakeholders identified a number of barriers to patient-led preference setting. These include
 - Lack of knowledge and awareness (among public and staff)
 - Inadequate IT systems leading to cumbersome processes which reduces buy-in.
 - Lack of awareness of and trust in a) how shared information will be used and b) how data will be kept secure from breaches and commercial profit
- Stakeholder identified a number of areas where work is required in order to create a sustainable system of patient-led preference setting and informant sharing. These include
 - The development of simple-to-use and linked up IT systems
 - Easy-to-use and flexible software interfaces that allow members of the public to actively engage with how and when their information is shared
- Stakeholder feedback indicated that challenges to distinguish between consent (for direct care) and patient-led preference setting (for research). In particular, consent and preferences were often used interchangeably and there is a need for further public engagement in this area.
- It is crucial to continue to build trust in systems (among citizens as well as practitioners) about what information sharing really means, what it is for, and how to do it safely.
- Building trust in systems requires recognizing organizational cultures and working towards organisational change in order to soften the barriers to implementing change and innovation.
- In part, organizational change and trust-building could be achieved on a) an infrastructural level (i.e. make sure the IT systems work easily and transparently) and b) on an engagement/education level (i.e. raise the profile of research – types of research and their benefits and why it matters).
- There are different cultures within the health and social care workforce – those who believe research should be undertaken with view to directly improving direct care and service planning and development, and those who take a longer view on research and support its academic purpose and benefits.

Discussion of Findings

Barriers to preference setting and patient information sharing can be divided into two kinds – those on a practical level and those of a more conceptual nature.

Barriers on a more practical level refer mostly to the need to link up health care services and provide users (both patients and health professionals) with the relevant IT systems to facilitate information sharing.

On a conceptual level, workshop participants identified barriers around awareness levels of data sharing, buy-in, organisational cultures, and attitudes toward information sharing, including the need to build trust in IT systems and their use.

Barriers and enablers: what would capturing permission for patient information sharing mean from stakeholder perspective?

Preference setting for direct care and service development

Generally speaking, participants support and welcome the idea of a platform that enables them to easily, quickly, and efficiently access patient information and share it with other health professionals and services. As they understand it, such sharing of patient information requires general consent from patients as well as easy-to-use and streamlined IT systems.

Preference setting for direct care

The sharing of patient information is seen as a tiered process, both practically and conceptually.

- Phase 1 = sharing patient health information for direct care so that services are better linked up and care can be administered quicker and more effectively.
- Phase 2 = sharing of patient information for service planning purposes that go beyond direct, face-to-face care.
- Phase 3 = information sharing and patient-led preference setting for research purposes.

There is a general consensus that sharing patient information with the aim to link up health care services and improve patient care is good and necessary.

“It’s good to share – improves care for the individual + for the future”

“Different systems need to work together”

[Relies on] “Integration of various IT systems”

“access to IT can be 20 minutes from finding a PC to using it properly”

“We have too many different systems that each department cannot access each other’s information”

“Quicker pathways”

“Joined up care + support” based on “simplified electronic solutions”

“Saving staff time if we don’t have to search for information + saving time between touch points”

“Communication with other organisations i.e. setting preference with GP then secondary services being able to access this”

Preference setting for research purposes

Sharing patient information for research purposes, however, is more complex. It relies on a culture change both among the health professions and the public.

“What is research – it is so vague that people will opt out because they don’t know what that means?”

Stakeholders felt that the required culture change is likely to only take place if the following key questions are answered:

- What is information collected for?
- How can frontline staff be trained to deliver a positive research message?
- Is the aim to improve direct care or to further research agendas?
- How can we raise awareness of the link between the two?
- Is the patient information that is shared for this purpose secure and protected from being used fairly, transparently, and for the greater good and not for commercial profit?

There are some positive voices among the stakeholders who feel that routinely making patient information available to be accessed as a research database is a good thing and will, ultimately, lead to improved care. On the other hand, most participants were reluctant to embrace the idea of sharing felt that, without appropriate public engagement, many patients would be, too.

“Research is the biggest challenge to succeed in. Why don’t we just get [on] with the rest and park research”?

“Why focus on research now? Move forward with a shared platform”

“Too fixated on research. Need to deliver benefits for direct care. People are far more likely to agree on sharing data for care purposes. The secondary purposes (service planning & research) will come later as trust grows”

“Not for Drug Companies”

“Research needs to be broken down more. Pop Health, drug trials, health data research”

“Public see everyday data being stolen. How do we make the public feel safe about sharing?”

Research is not the same as non NHS based research – in terms of trust + in terms of potential commercial benefit”

“Patients happy to share data from GP to hospital etc but research?”

Consent vs. Preference setting

There was some discussion around the differences between obtaining patient consent for direct care and preference setting with view to research purposes. The former was considered everyday business, though it come with its own challenges

“Informed consent – how do we inform without information overload?”
“Patients need to understand exactly what [they are] consenting to – means different things to different people”
“Do staff understand consent?”
“Why does consent have to be overcomplicated? Why do we need to ask for consent within health/health agencies multiple times?”
“Break down the fear of what we can and cannot do as clinicians with our without consent”

Using patient information for research purposes, in addition to direct care and service development, is the area where patient-led preference setting is most important and where stakeholders had more concerns about transparency and workability.

“More information needs to be given to public as to what is going to be shared”
“Communicate purpose of data sharing better”
“What are we telling patients about GNCR? How are we telling them about it?”
“What are you preference settings for?”
“Staff knowledge and understanding first – otherwise they cant’ support patients”
“People assume data IS shared”

The engaged patient

The idea of patient-led preference setting is built on a particular vision of an ‘ideal’, highly engaged, and actively involved patient.

IT systems require a certain level of flexibility to reflect the behaviours of such engaged patients.

Some participants were critical of the vision of patients who actively shape the ways in which their health data is shared and fear that this might exclude certain patient populations and exacerbate social divides. They raised several concerns around access and transparency.

“We must not make the health divide worse by making digital platforms the panacea”
“What happens to the people who do not want to use the digital platform?”
“People with limited experience of care, hospital treatment are less likely to understand the need for this”

“How can we make sure IT and screens are in an accessible place. I have been unable to reach three in my GP practice and specialist outpatients. I am a wheelchair user”

“Visually impaired – how can I use the system? Is it visible in my language?”

“What happens to your data if a citizen doesn’t register any preferences?”

“Vulnerable people (not registered)”

“How do we get more elderly included?”

“Could your medial history work against one? In future?”

What is needed to make preference setting successful and sustainable?

Stakeholder were clear that in order to develop a culture within healthcare and wider society, several things are required:

- IT systems that actually work therefore enabling the
- Building of trust that sharing one’s information is safe and ultimately allowing for a
- Culture change where there is a shared understanding between and among health professionals and members of the public that normalises the sharing of health information.

Preference setting requirement: Ease of use

Participants are clear that IT systems must be easy to use and the message for information sharing must be clear, simple, and straightforward.

On a structural IT level, participants commented on the lack of interconnected systems. This can often lead to having to ‘reinvent the wheel’ when it comes to finding, accessing, or sharing patient data.

“Too many IT systems being used for successful information sharing”

“true interconnected systems” are needed

“Transportability of data – systems talking to each other, same top level interface”

“IT changes require training, time, organisational change”

A good system saves staff time: “we don’t have to search for information + saving time between touch points”

The first step in successful and sustainable information sharing is getting patients online.

[I am] “shocked that we are not collecting emails”

Secondly, IT platforms must be end-user orientated and communicate the ‘how’ and ‘why’ of information sharing plainly.

“Trust Opt in/Opt Out (easy to change, easy to access)”

“Plain English explanations/FAQs”

“Make it easy to do”

“Common language and terminology, Plain English”
“Clear, uncomplicated, commonly used phrases and explanations”
“A single page, plain English description of what the GNCR is, what, why, how”
“Simple for users”
“Clear definition of what is required of the service user”
“Ease of use – simple usernames + passwords”
“Needs to be simple and consistent”
“[Provide] Examples of types of data being shared”

A number of participants had concrete suggestions relating to the technological aspects of information sharing.

“Idea: Highest percentage of technical usage is a smart phone. Why don’t we approach main manufacturers [for] pre-installed NHS app for patient to view [where] their data [is held] etc.?”
“NHS app should use Health Call preference model”
“GP check in kiosks. Set preferences following check in”
“Promote NHS numbers as unique identifiers. Perhaps give people a health card with this like NI number”

When it comes to preference setting, participants felt that a certain level of flexibility is required of IT systems. This includes

- Not having to repeat and revisit preference settings but being able to do so easily if required or desired.

“The need to only set your preference once”
“Requires the ability to change your mind at a later date = opt in/opt out over time”
“Opt out for genetic research” - “Opt in for clinical trials”
“Do citizens have the option to opt in or out and change preferences at any time?”
“Easy access to set/change preferences. Clear language (low reading age), simple structure”
“Ask once, apply all”

Some participants expressed surprise that health data is not already routinely shared across platforms and were sure that many patients, too, assume that this is the case.

“Why is this information NOT shared? – [e.g.] oncology patients”
“[We] underestimate our population – they do get it. Store cards – organisations collect their data”

Preference setting requirement: Transparency and Trust in IT systems and intentions of us

Participants agreed that if IT systems work well, levels of trust and necessary buy-in both from practitioners and members of the public will adjust accordingly. In addition, many participants commented on the importance of

- Transparency about how patient data are being stored and what they might be used for
- Transparency and the sharing of 'good news' stories is seen to lead to the required culture change both among the public and the healthcare workforce.

Building trust in systems – how secure is my data?

Protecting members of the public from data breaches was high on the list of concerns voiced in the workshop. Participants were clear that patients, as well as health practitioners, need to be able to trust that information is being used in safe and responsible ways and that data is safely stored.

“How are patients protected from data breaches?”

“Services changing providers of hardware and software must demonstrate robust protection of data”

“who manages and owns the system to do this”?

“Using the internet doesn't mean trusting the internet”

“Public see every day data being stolen. How do we make the public feel safe about sharing?”

By the NHS, for the NHS, not for profit

Generally speaking, stakeholders agreed that NHS branding was the easiest way to gain the public's cooperation and buy-in. Participants were clear that citizens must be assured that the information that is held about them is not for sale, safely stored, and used for and within the NHS with the main purpose to improve patient care.

“NHS branding for trust”

“NHS is NHS that 's how public see it”

One key concern was that shared data should only be used for research or care purposes only and not be sold for profit.

“Public concerns about selling data and value”

“People probably won't want this if they think people may be making money from their data”

“Will opening up access to personal data allow targeted advertisements tailored to my health needs e.g. hearing aids, diabetes?”

“Not for Drug Companies”

Culture Change and Buy-in

Practitioners were clear that in order to successfully and sustainably embed citizen-led preference setting, a culture change among the workforce as well as among the public is required. They identified the following issues:

- Raise awareness of the need and benefits of information sharing and preference setting across board should be raised.
- Normalise data sharing by sharing ‘good news stories’
- Acknowledge and address the fact that many organisations are (still) protective of ‘their’ data. This point was particularly made with reference to primary care, as GPs were seen to consider themselves as guardians of their patients’ health information.
- Improve the image of (academic) research among patients, publics and practitioners.
- Cascade trust building and public engagement by first establishing staff buy-in

“Communicate purposes of data sharing better [to member of the public]”

“Share benefits of research ‘what’s in it for me?’”

“Communication is the key to enable trust. [We need] different comms for different areas”

“Staff knowledge and understanding first – otherwise they can’t support patients”

“All staff in all sectors to believe that this is right and safe. It is the norm to share data rather than not”

“Education on what the research will be used for”

Doing this type of engagement work will automatically increase trust among and between organisations and stakeholder groups, which, in turn, will increase the likelihood of IT platforms to be actively and successfully adopted.

Recommendations – Practitioner expectations

For the Great North Care Record to be successful it would need to operate in a manner that satisfied the expectations of practitioners, service planners, and members of the public. These expectations include that:

- Continue and maintain public engagement exercises and effective communication strategies that promote the benefits and ‘good news stories’ of sharing health information.
- Through public engagement, work towards a required organisational culture shift so that sharing information is normalised
- Through a combination of public engagement and easy-to-use IT systems, raise the profile of (academic) research among health professionals and the

public whilst giving end-users effective tools to opt-in and opt-out (granularity)

- Ensure that IT systems are interconnected and reach across services and organisations. This helps avoid duplication of information and leads to more efficient patient care
- Ensure that user-facing platforms are easy to use and that their purpose is explained in plain English.
- Provide members of the public with as much assurance as possible about the safe storage and use of their health information. This builds trust and awareness.
- Remember that 'NHS branding' carries cultural and social significance and should be used in order to build patients' trust in IT systems and use of data
- Be mindful of how accessible and transparent information sharing pathways and platforms are and of the potential inequalities they may perpetuate or create.

Acknowledgements

With thanks to Corinne Anderson, Professor Paul Burton, Annette Chambers, Kathryn Common, Professor Mike Martin, Professor Joe McDonald, Fiona McDonald, Joel Minion, Professor Madeleine Murtagh, Dr Tejal Shah, Mark Walsh, Matthew Walsh, Louise Wilson and all the GNCR Network members and steering group.

Contact details

Dr Michaela Fay (PhD), 28 Eversley Place, Newcastle upon Tyne NE6 5AL
info@michaelafay.co.uk or www.michaelafay.co.uk

Great North Care Record
c/o North East Futures UTC, Stephenson Square, Newcastle upon Tyne NE1 3AS
gncr@ahsn-nenc.org.uk
www.greatnorthcarerecord.org.uk
@GreatNorthCare