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Submitted to Data Strategy for health and social care
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The Vision and Ambitions

Part 1: Empowering people

1 We all have different perceptions of what our health and care data may be:

text box (multiple lines):

We consider health and social care data is any information that pertains to contact, treatment or care a citizen has with or from any health and social care service that is stored or recorded in an NHS or provider system.

2 Our ambition is to give everyone greater access to and a greater say over their health and social care data. Health and social care data examples include results from a blood test, a diagnosed condition or interaction with specific health and social care services.

text box (multiple lines):

We believe that citizens should be empowered to actively involved in their health care and being able to access health and social care data is an important component of this. They should also be able to identify and correct, or have corrected in a straightforward manner, inaccuracies in the data.

Yes

text box (multiple lines):

Similar to power of attorney it would ideally be arranged while the patient was fit and able to grant consent, otherwise it would need to follow a specific process for someone to gain access to health and social care data for someone who can't grant consent to ensure it was robust and safe. There would also need to be similar arrangements of advocacy for individuals who lack capacity to understand and give consent.

3 We are committed to providing clarity over how your data is used and the need for this to be built on ethical principles. When thinking about the ethical principles that must be maintained when gathering, storing, and using health and social care data:

text box (multi-line):

We believe it is important that citizens know that data collected about them is processed accurately and is used ethically. Succinct and specific statements about what this means would be important to ensure citizens understand what is meant by ethical use of personal data.
DHSC commissioned a review to look at improving care through use of data which has useful information
https://www.gov.uk/government/news/goldacre-recommendations-to-improve-care-through-use-of-data

Very Important

Text Box (Multiple Lines):

It is important that health and social care professionals are appropriately trained, feel supported and confident in data sharing with clear guidance to enable an understanding of circumstances where data should not be shared. Mandatory information governance training on accessing and sharing data appropriately is already available and this must be kept up to date. Staff must also be aware of the Caldicott principles and how they apply to their working practice.
They also need assurances that all the data being collected is useful, is not just being collected to complete a form and see that if data is only collected when needed.
A major concern of the public is around data use, storage and sharing. The right foundations are essential (in terms of the technical/security, the legalities, and the regulations around this) to providing patients and the public with the assurance they need to feel safe and happy with their data being shared.
The public need to see appropriate sanctions for healthcare professionals who fail in their duty of confidentiality along with assurance and information on how their patient data will be handled.
It is also important that patients have access to their health and care data and be enabled to share this with others if they so wish.
There also needs to be a clear distinction between who has access and what access they have. Some healthcare professionals might only need read access to certain parts, some read and write access would be beneficial e.g., pharmacists in the community with read/write access could record over the counter medicines or note any issues reported to them.

4 When considering sharing of your data across the health and social care sector:

Text Box (Multiple Lines):

Data would ideally only be shared with those involved in the direct clinical or social care of a patients or for the purposes of service development, where anonymisation/pseudonymisation should be considered. Where there may be shared access to a patient record, this should only be accessed when appropriate and for the purposes of patient care. With appropriate approvals (e.g., Caldicott) it might be appropriate to share anonymised/pseudonymised/aggregated data for the purposes of service development/audit/health improvement.

Sensitive data such as gender realignment is a contentious area where individuals may not wish this information to be available, but there are situations where knowing the phenotypic sex of the patient could be crucial in treatment decisions.

Text Box (Multiple Lines):

We believe that health and social care data can be shared for improvement work, e.g., service development or health Improvement. We believe that this data should be anonymised/pseudonymised or if there is a legitimate reason for sharing non-anonymised data this is done with appropriate approvals (e.g., local Caldicott) and is done ethically.

5 More people are using wearable devices to track their own health including sleep activity, mindfulness, heart rate, blood pressure and physical activity.

Not Answered

Text Box (Multiple Lines):

We believe that data collected from wearable devices might be useful to supplement data collected by healthcare professionals providing direct patient care. We believe that the highest quality of data comes from those devices that are licensed (and regulated) for use clinically (e.g., interstitial fluid sensors that are prescribed within the NHS) and we believe that health and social care should prioritise the use of data from wearable devices to those devices of the highest accuracy and quality.

Part 2: Empowering Those Delivering Health and Social Care Services

6 Considering skills and training opportunities for those delivering health and social care services:

Ranking Table - Data visualisation:
6

Ranking Table - Understanding/use of management information by managers:
1

Ranking Table - Understanding of what data exists and where to find it:
2

Ranking Table - Knowledge of how to access data:
5

Ranking Table - Confidence in using data:
3

Ranking Table - Understanding of governance:
4

Ranking Table - Other (Please specify below):
7

Single Text Line:
Understanding clinical coding

Text Box (Multiple Lines):

We believe it is imperative that staff have an understanding of interpretation and interrogation of data in order to make best use of the data collected. There should be appropriate training at both under and post graduate level with courses updated as changes occur.

Text Box (Multiple Lines):

It is essential that a patient’s health and care data are collected and accessible from a single source but that can be achieved be through connecting data sources that are not in a single location. This would require data to be interoperable i.e., recorded with the same terminologies to minimise the risk of errors or misinterpretation.

7 Thinking about improving the quality of data that is used by health and social care services:

Text Box (Multiple Lines):

1. Better interoperability across systems and care providers with the wider sharing of, and access to, data. One way to do this would be a shared patient record.
2. Supporting existing practitioners to upskill with the necessary analytical skills to make sense of collected data.
3. The need for single unified clinical coding system

Text Box (Multiple Lines):

Our role is to advocate for the profession to enable pharmacists to provide the best holistic care for patients possible. Having full access to information to support care is going to be critical to pharmacists as the profession moves towards more and more clinical service delivery and we will work towards ensuring pharmacists have that access.

Text Box (Multiple Lines):

Any data held by the private sector or those that sit out with the NHS, relating to a patients care that could impact on care provided by the health and social care sector e.g., hospice care. It would have to be decided what data that included, it may not be necessary to know about every minor cosmetic procedure carried out, for example, but private treatment for chronic pain might be helpful to share. However, any implants or injectables should be recorded in the unfortunate event of a recall. NHS implants are recorded in the implantable device database, and it would be more robust if all implants and injectables were recorded in the same way.
In addition, there is ample evidence that the biopsychosocial determinants of health and health behaviours are determined by social circumstances/education/income. Adding key information from sources other than health and social care (e.g., Education, HMRC, Police) to the patient record could be a powerful mechanism for improving the outcomes for patients. This would allow healthcare professionals to gain a better understanding of the patient situation and would mean they were better able to tailor health or social care to meet their patient's needs. However, there could be important information for providers of care which may require to be 'hidden' from the individual (but still kept as part of their record) e.g., that the individual can be violent. This information is currently held as a 'special note' in ECS and is extremely helpful for healthcare professionals such as paramedics as it allows them to operate in a safer manner and not expose any provides to a potentially unsafe situation.

8 We have heard that a more consistent approach to data standards will help improve insight and outcomes for individuals:

Agree

Text Box (Multiple Lines):

Without agreed and mandated standards there is the risk that variations occur which can lead to inaccuracies in recording of data. However, before implementing these standards, the unintended consequences would need to be carefully considered. One outcome of this could be that the setting of standards to ensure quality stifles innovation and development because those standards are not sufficiently nuanced or flexible so don't fit easily into the needs of health and social care. The OpenEHR model is one example which is sufficiently flexible to allow for those nuances.
We do believe data standards are important where similar data is generated from different sources and where this information is shared because it is important for the care provided by health and social care to citizens to be consistent and easily understood. A couple of key examples are the recording of diagnosis and the recording of treatments (such as medicines) where there are already UK wide coding sets being used (SNOMED CT and dm+d).

9 When considering the sharing of data across Scotland's health and social care system:

Agree

Text Box (Multiple Lines):

We agree that it should improve the quality of service the individual receives, but only if staff are appropriately trained in accessing the data and that there are workflows developed to ensure that the access to the data happens.
Pharmacists provide patient care in several different settings and better sharing of data and information would be transformative. Full medication histories should be available in community pharmacy settings which would allow clinical decisions to be made with all the necessary information allowing a seamless patient medication journey. The current model of access to ECS for Pharmacists needs to be completely rethought for a more modern and auditable access to this type of information. The current model is broken and needs to be fixed. In hospital settings, better sharing of information would remove the need for time consuming medicines reconciliation which also reduces the risk to patients of transcription errors. Changes to patient's medication will be able to see by all involved in their care immediately and communication between those providing care would be improved.
It is essential that health and care professionals have access to the data they need to provide the best possible care to the person. Many people are now living with multiple long-term conditions, and from a medicine's safety perspective, it is essential to know all the medicines a person is taking, any reasons for changes to these medicines as well as what conditions they have been diagnosed with to improve patient and medicines safety. Patients are often the only 'constant 'in their healthcare and currently carry the burden of information sharing between multiple medical teams and organisations. Many people must repeat their stories and information (either because it's not adequately documented or shared across systems that aren't intra-operable) and this is a constant source of frustration and wasted time for healthcare professionals and patients alike. The lack of joined up systems poses substantial risks for medicines related harm especially in vulnerable older people.

10 Thinking about the actions needed to improve the quality of management information and internal reporting data across health and social care:

Text Box (Multiple Lines):

The single health care record for the patient should also be single record of all the citizen's interactions with health and social care that is a record of the care provided by whom, what, where and when. Ensuring this is recorded consistently, accurately and in real times (or as close to real time as is practical) will substantially improve the quality of management information and internal reporting data. If we ensure we get the clinical coding correct upfront and the input of it is of a consistently high standard, then the management information should be able to flow easily from this.

Text Box (Multiple Lines):

In addition to a single comprehensive health care record having this structured in a consistent manner and to consistent data standards will ensure high quality business intelligence and reporting.
A modern data platform which provides AI/ML-based analytics on this 'big data' would help to generate 'real-time' or 'close to real-time' monitoring of the entire health and social care system. It would enable the early identification of changes in service usage, increasing patterns (or clusters) of illness (or

need). This is only something that can be done post-hoc currently.

11 Thinking about improving the quality and ability to reuse data sets across health and social care setting and for innovation & research:

Text Box (Multiple Lines):

We believe that information on diagnosis, treatment (what, where and when and by whom) and outcome is a key data set for each citizen that can be reused not only to ensure patients only have to tell their story once but also for innovation and research with appropriate data control and consideration of ethics. There are also data which, once recorded, should not need to be repeated by the patient such as demographics, advocacy, power of attorney and key contacts.

Part 3: Empowering Industry, Innovators and Researchers

12 When considering the ethics of accessing health and social care data for commercial, development and research purposes:

Text Box (Multiple Lines):

National data sets can be used to demonstrate the effectiveness of quality of services in all settings. Data on prescribing, review, and administration of medication should be used to identify trends which may indicate a need for service change or changing health needs of the populations. Clinical outcome data should be gathered and should link patient outcomes with the prescribing and administration data which will show the impact of services on improving population health to be determined and service improvements to be made. This would be far more representative than gathering data on number of interventions provided.

Text Box (Multiple Lines):

It is important to be transparent about what a patient’s data may be used for and who will use it. If the data is intended to be supplied to an organisation out with the health and social care network e.g., marketing companies, etc. this must be made clear and not hidden at the bottom of a page to allow patients to make a truly informed choice about their information and who can access it. Patient-level data from health and social care made available to industry and innovators must be anonymised on order to ensure this data is shared in accordance with GDPR.
A public health campaign to reassure citizens that the NHS will never ‘sell their data’ i.e., personal identifiable data, but will include de-identified data as part of a research proposal could be helpful to allow citizens to understand how their data is managed.

Text Box (Multiple Lines):

Using data for a purpose where there has not been permission granted for it to be used. Any use situation where an individual may be disadvantaged by their health and care data in a commercial situation e.g., using genomic data to dynamically alter life insurance premiums, or to refuse to insure on that basis.

Text Box (Multiple Lines):

A publicly viewable application process would allow public scrutiny and encourage transparency plus a regular audit process with publicly available results which is carried out independently but funded by the companies.

13 We want to create an infrastructure that supports access to data for research and innovation in a safe, secure, and transparent way:

Text Box (Multiple Lines):

Research indicates that "social license" is important when using data for research i.e., people are willing for their data to be used to help others for the common good but in return for this, they want an assurance of confidentiality and transparency on how their data will be used.
Access to national safe havens is already set up, so industries and research partners should already have access to data which is de-identified but retains its referential integrity. The NHS/academic joint bodies which manage access to these data need to improve their process efficiency to reduce backlogs though.

Text Box (Multiple Lines):

Lack of a single shared care record where all a patient’s information can be accessed on appropriate levels by those providing care. The lack of interoperable data terminologies which would minimise the risk of misinterpretation of data.

14 Used appropriately and well, technologies such as Artificial Intelligence can help to improve decision making, empower health workers and delivery higher quality health and social care services to citizens, improving how you receive health and social care services:

Text Box (Multiple Lines):

AI can enable specified learning to reduce manual data interpretation and processing. AI can also detect relationships and patterns in data which humans can’t, therefore new insights may be gained.

Text Box (Multiple Lines):

The extent and remit of the learning should be predefined and review regularly to allow appropriate development.
It would be important to address the underlying risk of hard baking errors into the core AI algorithms through not adequately accounting for biases, implicit bias, sampling bias, temporal bias, over-fitting to training data, poor management of edge cases and outliers.

Having “clear boxes” rather than “black boxes” will provide an opportunity for independent review of the core AI algorithms.

Some AI may qualify as a medical device and therefore be subject to regulation. There is work ongoing to see how AI can be included into new UKCA legislation for software as a medical device. The issue of upgrading AI and the impact that can have on functionality and learning pathway of the machine would need to be addressed. It would not be practical to implement AI only to have to start from scratch each time and upgrade was necessary.

Overall Reflections

15 Please use this box to provide any further information that you think would be useful, which is not already covered in your response.

Text Box (Multiple Lines):

About you

What is your name?

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Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:
Royal Pharmaceutical Society

If answering for an organisation, from which sector is your organisation?

other

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:
Very satisfied

Please enter comments here.:

Only issue was the questions where you were given and option to agree or disagree or if something was important or very important there was no opportunity to explain why you gave that response.

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:
Very satisfied

Please enter comments here.: