Data Strategy for Health and Social Care

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About us

We're RCOT, the Royal College of Occupational Therapists. We've championed the profession and the people behind it for over 80 years; and today, we are thriving with over 35,000 members. Then and now, we're here to help achieve life-changing breakthroughs for our members, for the people they support and for society as a whole. Occupational therapists in Scotland work in the NHS, Local Authority social care services, housing, schools, prisons, care homes, voluntary and independent sectors, and vocational and employment rehabilitation services.

Occupational therapy helps you live your best life at home, at work – and everywhere else. It's about being able to do the things you want and have to do. That could mean helping you overcome challenges learning at school, going to work, playing sport, or simply doing the dishes. Everything is focused on increasing independence and wellbeing.

It's science-based, health and social care profession that's regulated by the Health and Care Professions Council.

An occupational therapist helps people of all ages overcome challenges completing everyday tasks or activities – what we call 'occupations'. Occupational therapists see beyond diagnoses and limitations to hopes and aspirations. They look at relationships between the activities you do every day – your occupations – alongside the challenges you face and your environment.

Then, they create a plan of goals and adjustments targeted at achieving a specific set of activities. The plan is practical, realistic, and personal to you as an individual, to help you achieve the breakthroughs you need to elevate your everyday life.

This support can give people a renewed sense of purpose. It can also open up new opportunities and change the way people feel about the future.

Our response

Section 1: Empowering People

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

1A. When considering the term 'your health and social care data' what does this mean to you and what do you consider it to be?

The Royal College of Occupational Therapists (RCOT) believe that data sharing with service users is an opportunity to empower individuals and can facilitate working in partnership with those accessing services- if appropriate GDPR and IT permissions are in place. Service user's accessing their own data with ease as well as actively contributing to their own health and social care data will contribute to person centered practice and would be a step towards a more innovative health and social care system appropriate for its time.

The RCOT believes that is it important that the term 'your health and social care data' encompasses both clinical and non-clinical data. It should also recognise that our health and social care data is mostly generated by health and social care systems, but some service

users are also now collecting their own data through smart apps and technology, so going forward it will be important to take this into consideration also. Health and social care data can also encompass anything from medical facts about service users to general notes written by the medical professional, so it is important that the definition is conveyed and articulated appropriately.

The RCOT also believes that there are potential issues around who can access the data and with whom it could be shared, and on the extent of the data made available. There is understandable concern from service users about control over their personal information. The scope of what 'health and social care data' is needs to be carefully understood and conveyed to the public. The RCOT would like to understand if sensitive incidents such as domestic abuse, criminal incidents etc. would also be included as health and social care data or if this would remain within health and social care data systems?

The RCOT also have several questions around who keeps the service user's record up to date. Is there an expectation to be placed on the service user to update their records or to check the accuracy of the information contained within? Or will this function be carried out by a health professional – if so, whom? If a service user sees a lot of healthcare professionals, is there a system in place to ensure the records are updated?

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.

2A. When thinking about accessing your own health and social care data, what data about you would be your priority for having access to and greater control over?
A large part of the work occupational therapists does, is empowering people to support themselves and live their best life independently. The RCOT believes that there should be a system in place for service users to record self-management treatment and what they are undertaking at home to manage their condition. For example- being able to link with an external app which records engagement in exercise, mindfulness etc. Occupational Therapist's work collaboratively with service users to develop a health/social care plan that will allow them to participate in the activities they need and want to participate in daily. The RCOT views the service user's input at a vital part of their health and social care plan. Therefore, their contribution to their health and social care data is vital also.
However, our workforce should feel supported by the new data strategy to write their notes freely and accurately particularly when there is a disagreement with a service user. Healthcare professionals should be supported to practice good note keeping.

The RCOT has questions around the role of consent of the service user regarding greater access and say over health and social care data. If a service user does not consent to their information shared with other healthcare professionals, is the ultimate decision with the service user or can this be contested by health and social care professionals? Further clarity on who has ownership of the data would be welcomed.

There also should be clarification within the guidance if there will be changes to how quickly individuals can access their data, currently this is 30 days with a written request. Furthermore, simple administrative processes need to be addressed to facilitate service users having access to their data. For example, will service users be copied into letters from one healthcare professional to another or are the letters written to the service user with the

healthcare professionals copied in, which The RCOT believes is a much more person-centered process of working. Additionally, it is important to understand why a service user wants access to their data. For example, if an individual has multiple conditions and sees multiple healthcare professionals it could be beneficial for the individual to have access to all of these records to keep track of what is going on with their own health and social care.
It is important that the Scottish Government understands and addresses the existing barriers to citizens in accessing their health and social care data. For example, it is crucial that no NHS or local authority healthcare practice creates a financial charge for service users to access their data in any format. In adding a financial charge, this would create financial barriers and a wealth divide.

2B. When considering the rights of individuals who are unable to interact with their own health and social care data, do you feel that delegating access to a guardian/carer/trusted individual would be appropriate? Yes
The RCOT believes there should be a process in place to delegate access to a guardian/carer/ trusted individual when the individual in question is unable to interact with their own health and social care data. For example, dementia may affect an individual's ability to make decisions and mental capacity and they may need support in making decisions around their data. As the service user's situation fluctuates throughout their health and social journey, there needs to be a process in place as to who has the responsibility for continuing to review their situation with regards as to who has access to their data. The RCOT believes that the responsibility over a service user's data should not rely with the health and social care professional or organisation who has access to and writes in the individuals' record.

The RCOT has identified issues regarding vulnerable children and young people when delegating responsibility to access to their health and social care data. It is crucial that there is an extensive process in place to ensure the safety of vulnerable children. Those responsible for the child's data must have sufficient background checks to ensure the child will not be at risk if this data is shared with the chosen guardian or carer.

The RCOT feels that delegative access to guardian/carer/trusted individual is appropriate when considering the rights of those unable to interact with their own health and social care data.

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 (read our ethical principles on gov.scot) that must be maintained when gathering, storing, and using health and social care data:

3A. What information would you find most useful in providing clarity over how your data is used in a consistent and ethical manner?
The RCOT believes it would be beneficial for the new data strategy to have a platform accessible to citizens to address the myths around how their data is handled. Different communities across the country will also have varying concerns and will need to be reassured in different ways due to scepticism through fears of racism, sexism, homophobia etc.

The RCOT believes it is crucial that there is transparency around how many people have access to the data and how they can access the data. The RCOT would be interested in how digital access can be captured to make this clearer to the population.

The RCOT believe health and social care professionals should have positive conversations around data access with their service users and encourage service user to take ownership of their own health and social care data. Healthcare professionals should support service user's access to their health and social care data to be fully informed.

3B. To what extent do you believe it is important to collect data to enable our health and social care services to understand how they are serving those with protected characteristics? Very important.
It is critical that this data is collected and that it is collected accurately to develop services that best serve the population.

Some members of RCOT share concerns about how this information is to be used. They feel that the risk of privatisation across health and social care sector could leave citizens with protected characteristics open to vulnerability if their information is shared without their consent. The potential risks of the private sector accessing patient data should be addressed in the consultation analysis.

3C. When thinking about health and social care professionals accessing and using your health and social care data, what more could be done to improve your trust?
As discussed previously, the RCOT believes it is critical that there is transparency around who is accessing the individual's data and what is it being used for. It should be made clear to the public what data is being gathered and what is being done with this data. Also, the RCOT would advocate for a record to be kept of who has had access to an individual's data. It is also important to ensure the individual is made aware if they are being referred to another specialist and to advise them that new person will have access to their data, and they could potentially be contacted. With increasing phishing and online fraud, the service user should be aware of who may contact them.
Members of the public can often be surprised that health and social care professionals do not have access to all their records when moving between NHS services and local authority teams. If health and social care staff are to work as one integrated body, the data systems should reflect that.

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

4A. Are there any health and social care situations where you might be uncomfortable with your data being shared?
The RCOT believes it is important to understand what exactly is described as a 'health and social care situation' as this could encompass many different sectors such as justice and education for example.

From our members experiences as Allied Health Professionals (AHPs), many service users' experiences across wider health and social care services, social security and the justice system can influence how they feel about their data being shared and many will be more cautious about their data being shared out with the professionals in these sectors. Furthermore, the increasing use of the non-statutory organisations in health and social care services may have an impact on how service users may feel about their data being shared with non-statutory organisations. This is more likely if the non-statutory organisations do not explicitly say what they are doing with the service users' data.

4B. Under Data Protection legislation, your health and social care data can be shared in order to administer care. For what other purposes would you be comfortable with

your health and social care data being shared within the health and social care sector?
The RCOT believes a citizen's data should only be shared if it would be of direct benefit to their health and social care or if requested by law enforcement for the general safety of the wider population. Internal research and innovation projects may also benefit from access to anonymised health and social care data.

Whilst an individual's data can be valuable for research purposes it is crucial that we can identify what we are learning from the data. If the data is being shared for research purposes, then it is crucial to be transparent, anonymous and have the individuals' full consent. Data should be anonymised where possible when sharing for research purposes.

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

5A. Do you gather your own health data for example measuring activity, sleep patterns or heart rate through a mobile phone or watch?
If yes, would you want to share this data with health and social care professionals, and for them to use it to improve the services you receive? No answer.

Section 2: Empowering Those Delivering Health and Social Care Services

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

6A. What are the top skills and training gaps relating to data in Scotland's health and social care sector?
• Data visualisation
• Understanding/use of management information by managers
• Understanding of what data exists and where to find it
• Knowledge of how to access data
• Confidence in using data
• Understanding of governance

After consultation with our members, the RCOT believes that there is a training gap regarding being able to understand and analyse data. Some members are unsure on what conclusions can be drawn from data and how this may help health and social care practices. Training on data collection and usage would be beneficial and some services may benefit from "Data Champions". The systems employed by health and social care services to collate data should be streamlined and accessible to improve ease of use from staff.

6B. How do you believe they should be addressed?
The RCOT believes there should be a national training programme on how to collate and analyse information from service users particularly staff taking on more senior roles. Furthermore, it would be useful for health and social care professionals to understand how the data they are collecting is relevant to the organisation they work and the services they deliver.

6C. What actions must be taken as a priority to ensure that the public have access to health and social care data that they can understand and use?
The RCOT believes that it is vital to be transparent when informing the public on how their

data is collected, how it is used and who can access it. Moreover, the public should be informed on how to access their own health and social care data and what rights they have in connection with this information.

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

7A. What three things are needed to improve quality and accessibility?

1) Occupational Therapists work across work across the health and social care systems and recognise a disconnect between NHS and local authorities regarding sharing and storing data. There are differing IT systems are used across acute, community and primary care teams impacting the ease and timeliness of which information is shared. The new data strategy should reduce the need for service users to repeat their story to multiple health and social care professionals. A shared data system would ensure the service user would not have to repeat themselves to each different occupational therapist. Health and social care professionals should not be required to rewrite the service user's history with each new referral. This would minimise the time spend on administrative tasks and allow the professional to spend more time building a relationship and supporting the individual.

2) The RCOT believe that access and connectivity to IT systems and internet are needed in every health and social care setting, with access to reliable Wi-Fi. Many service users will live within areas where the signal and Wi-Fi is not as reliable, and this can prove troublesome when trying to access online forms and record information. This is important for both the service users and the health and social care professionals working within these communities.

3) When service users are gaining access to their data, the system they use must also facilitate that data to be displayed in a way that it is easy for them to understand.

7B. If you are responding on behalf of an organisation, what role do you believe your organisation has to play in improving accessibility and quality of health and social care data? No answer.

7C. What data, that is generated outside of the health and social care sector, do you think could be made available to health and social care professionals to improve health and social care outcomes in Scotland?

The RCOT believes the new data strategy would need to explicitly address what is meant by 'outside the health and social care sector' as this could be understood in many ways by individuals and organisations.

If the data is being shared with an organisation such as the third sector or agency with the appropriate consent for the benefit of service users, then we would be supportive of this. Information from the third sector could be imperative to improving care and services, for example Alzheimer Scotland sharing common experiences for those experiencing a diagnosis of dementia or data from Shelter on health and social issues relating to our homeless communities. However, if the NHS and Scottish Government are sharing health data with organisations full consent or anonymising is required.

Furthermore, in relation to the health and social care of children and young people, data from the education sector could be useful in providing more information about the child's life and developmental progress.

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

8A. To what extent do you agree with the proposal that Scottish Government should mandate standards for gathering, storing, and accessing data at a national level?
Agree.
The RCOT agree that there should be a mandated standard for gathering, storing and accessing data at a national level. However, this should only include minimum standards. Having minimum standards allows for consistency but also a degree of flexibility that permits different health and social care settings to create and store data that is useful to them rather than a one-size fits all approach. Furthermore, having minimum standards means that if health and social care professionals are moving to work in a different part of the country or different health and social care sector then there is no additional training required for different systems. It also removes the 'postcode lottery' on data systems across the country so no one area is better than the other for collecting and storing data.

8B. What data standards should we introduce?

- What data is being gathered
- How it is being used
- How it can be accessed and by who
- The data systems being used

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

9A. Do you agree with the idea that greater sharing of an individual's health and social care data between the organisations in the health and social care sector will lead to better quality services? Agree.
Allied health professionals work across a range of services from NHS acute to community, third sector and local authority services. Having access to shared data between organisations would cut down how many times service users would have to tell their story and allow for more time for the health and social care professional to care for and to build the relationship with the service user.

9B. If you are a clinician – how could we improve patient safety through better sharing of data and information?
As stated above, the sharing of information between NHS and local authority teams will contribute to quality services and patient safety.

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

10A. What are the priority pieces of management information needed (that are not currently available) to provide better health and social care services?
The RCOT believes that it would be of benefit to health and social care management to be able to quickly collate data that improves future service planning. For example, it is important management can access accurate and up to date stats on how many service users are accessing the service, where these referrals are coming from and service user outcomes.

Feedback from service users would be beneficial to future service planning.

10B. What is needed to develop an end-to-end system for providing business intelligence for health and social care organisations in Scotland?
It is important that when creating the new data strategy and systems that the Scottish Government recognise that many health and social care staff are not trained in data management. They will require further training to ensure they gather, quantify, structure data in the most productive and efficient manner. As the workforce is already stretched, the Scottish Government should be cautious that the new data strategy does not unduly increase the work burden on health and social care professionals.

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

11A. What key data sets and data points do you think should be routinely reused across health and social care to reduce duplication of effort and stop people having to re-tell their story multiple times?
Occupational therapists work across teams in both health and social care settings across Scotland. An IT system that is fit for integrated health and social care services is essential to ensure all staff involved in a service user's care can provide a seamless service by viewing that person's entire health and social care journey. For example, if a community occupational therapist from the local authority completes an assessment of the client's home it is beneficial if the NHS acute occupational therapist can access this assessment if the client needs to be admitted to hospital. This information would support with discharge, future care and rehabilitation planning.

NHS boards and local authorities often use very different IT and record keeping systems which limits the ability to have a clear and seamless handover between teams. It is easy for important information to be missed which results in staff spending extra time sourcing the correct information when they could be using that time to support the individual.

Section 3: Empowering Industry, Innovators and Researchers

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

12A. How do you think health and social care data should be used by industry and innovators to improve health and social care outcomes?
The RCOT believe that health and social care data is vital for future planning. It's particularly important to gain a better understanding of the needs of our workforce and communities and the workforce planning and training which will be required to meet those needs.

12B. How can industry and innovators maintain the trust and confidence of the people of Scotland when using their health and social care data for research purposes?
The RCOT believe transparency is key when building the confidence of the people of Scotland. The necessary ethics and governance are required to ensure that data is protected. Clear goals of the research are required.

12C. What do you believe would be unacceptable usage of Scotland's health and social care data by industry, innovators, and researchers?
Health and social care data mustn't be used for profit or used to exclude citizens based on

their health characteristics.

12D. How should industry, innovators and researchers be transparent about their purposes in accessing, and the benefits of using, health and social care data? The RCOT believe that when using public health and social care data the researchers and innovators should report to public bodies and the public who will have the necessary mechanisms to hold them to account.

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

13A. How should the Scottish Government seek to store and share health and social care data for research in order that it can best facilitate easier access that is still safe and secure? No answer.

13B. What do you believe are the key data needs and gaps that are faced by industry, innovators, and researchers when it comes to Scotland's health and social care data? No answer.

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:

14A. What are your views on the benefits of using AI to improve the delivery of health and social care services? No answer.

14B. What safeguards do you think need to be applied when using AI? No answer.

Contact

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