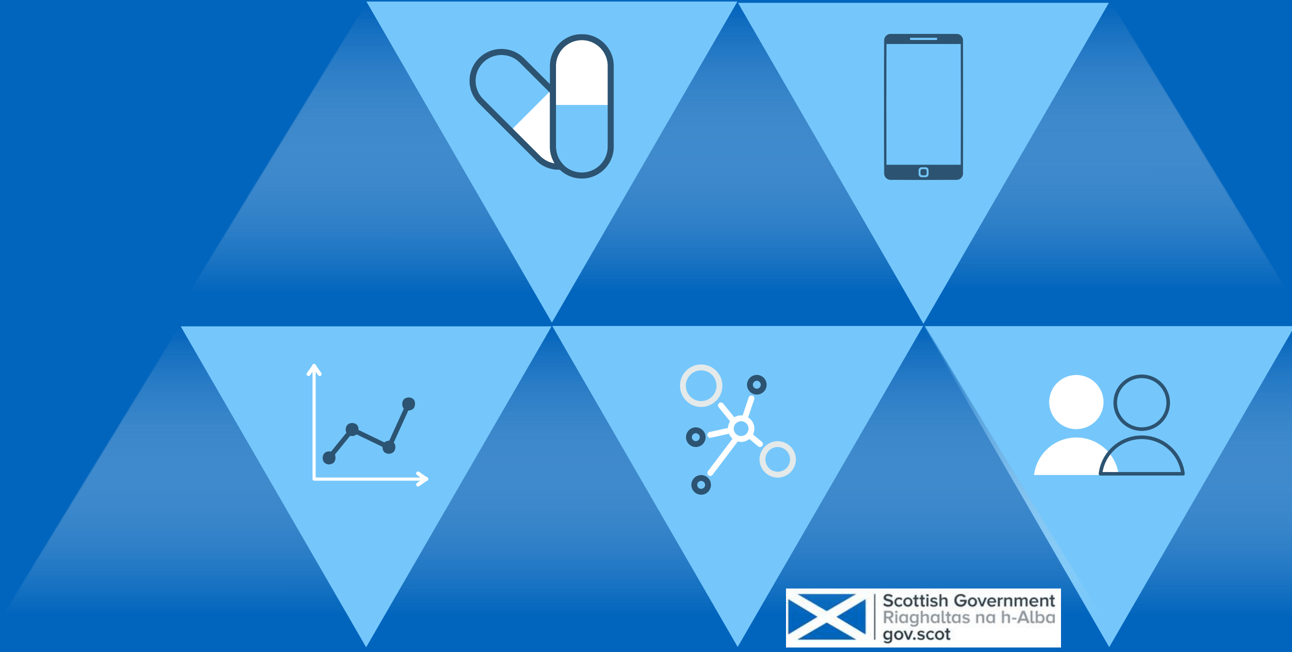

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Scottish Cancer Patient Reported Outcome Measures Forum

Key learning from Meeting 4 - 21st March 2025

The 4th SC PROMs Forum event 21st March 2025

The online event featured a comprehensive agenda with 3 speakers including academics, Scottish Government and those working with PROMs in clinical practice. A total of 74 people registered and 53 attended. The Scottish Cancer PROMs Advisory Group, with help from previous Forum events, created the SC PROMs Toolkit. The aim of the event was to showcase the Toolkit and discuss how to ensure successful collection and use of PROMs as part of routine care through a series of workshops ("breakouts").

Many thanks to the speakers and breakout facilitators who contributed to the event, all attendees who participated, posed questions and commented, the Executive Team for organising and facilitating the event, and the SC PROMs Advisory Group for their steer and support.

The Scottish Cancer PROMs Forum (SC PROMs Forum) is an open collaborative space for anyone to contribute and learn from current and future work in Patient Reported Outcome Measures (PROMs) and how they can be collected as part of routine care to better understand and manage the impact that cancer medicines have on quality of life. The Forum will support the Advisory Group in the implementation of the PROMs Core Principles and Toolkit and reviewing their effectiveness in supporting the collection and use of PROMs in clinical practice in Scotland.

On the next pages you will find the event agenda, key messages from the breakouts, and our plans moving forward. You will then find biographies of each speaker and details of how to get more information on the Scottish Cancer PROMs Forum and Advisory Group.

Scottish Cancer PROMs Forum Meeting 4 Agenda
Friday 21st March 2025 1:30pm - 3:30pm, MS Teams Webinar

Introduction	Time	Chair: Peter Hall
Welcome from Scottish Cancer Patient Reported Outcome Measures Advisory Group (SC-PROMs AG) and introduction to the SC-PROMs Forum	1:30pm – 1:35pm (5 mins)	**Emma Dunlop** (Research Associate, Cancer Medicines Outcomes Programme (CMOP) University of Strathclyde, Co-Chair of the SC-PROMs AG)
Presentation: Large-Scale Implementation of Electronic Patient Reported Outcome Measures (ePROMs) Into Routine Oncology Care at The Christie NHS Foundation Trust	1:35pm – 1:50pm (15 mins)	**Dr Thitikorn Nuamek (Pao)** (Clinical Research Fellow – ePROMs, The Christie NHS Foundation Trust, Manchester)
Presentation: Realistic Medicine update on on PROMs	1:50pm – 2:00pm (10 mins)	**Dr Stephen Martin** (Realistic Medicine Policy Team, Scottish Government) **& Dr Ann Wales** (Programme Lead, Knowledge and Decision Support, NHS Healthcare Improvement Scotland)
Scottish Cancer PROMs Toolkit • What is the Toolkit? • How was it developed? • What does it contain? Questions	2:00pm – 2:20pm (20 mins)	**Emma Dunlop** (Co-Chair SC PROMs AG / Researcher for Cancer Medicines Outcomes Programme (CMOP), University of Strathclyde)
Break	2:20pm - 2:25pm (5 mins)	-
Breakouts		**Chair: Emma Dunlop**
Breakout Session 1: A: What does a “good use of PROMs” look like? B: Getting past the pilot C: Beyond the patient information leaflet	2:25pm - 2:40pm (15 mins)	All 3 breakout discussions will happen during each Session. Simply join a discussion that you haven’t yet participated in as the Sessions go on. Breakouts will be supported by a facilitator and are interactive- you can speak as well as provide comments using the Chat. Please read the Participation guide provided nearer the time.
Breakout Session 2: A: What does a “good use of PROMs” look like? B: Getting past the pilot C: Beyond the patient information leaflet	2:40pm - 2:55pm (15 mins)	
Breakout Session 3: A: What does a “good use of PROMs” look like? B: Getting past the pilot C: Beyond the patient information leaflet	2:55pm - 3:10pm (15 mins)	
Discussion		**Chair: Peter Hall**
Brief sharing of what has been discussed in breakouts from facilitators	3:10pm - 3:25pm (15 mins)	You can use the Q&A function to pose questions, or the Chat function to make comments. Please read the Participation guide provided nearer the time.
Thank you	3:25pm - 3:30pm (5 mins)	**SC PROMs Advisory Group Executive Team**
Close		

Breakout Descriptions

On the day attendees took part in all three of the discussions. The breakouts aimed to help the SC PROMs Advisory Group to hear thoughts, opinions and possible solutions to some of the key challenges affecting PROMs implementation.

Breakout	Description/Points Covered
A: What does a "good use of PROMs" look like?	When a clinical team decides to routinely collect PROMs from patients, they should record how well PROMs implementation (and use of PROMs data) is going. So, what does good use of PROMs look like? What information do teams need to collect to be able to track progress and make positive changes to how they collect PROMs? And what can get in the way of doing that well? This discussion shouldn't focus on the patients' progress or the PROMs themselves, but more so on how we best define what a good use of PROMs looks like in routine care.
B: Getting past the pilot	Many uses of PROMs are short-term and rely on funding for a limited time e.g. pilots or research projects. What needs to be done to get past the "pilot" stage and make sure PROMs can be collected as part of routine care longer-term?
C: Beyond the patient information leaflet	As we've discussed before, patient engagement is vital to successful collection of PROMs. But what might patients think about how their data is being used beyond the walls of the clinic? How do we build trust? And how do we move beyond the "lay summary" to properly inform and involve patients in how their PROMs data is used?

Breakout A: What does a “good use of PROMs” look like?

Patient experience

- PROMs should enable patients to feel that their physical, mental and emotional wellbeing, and the coordination of their care, are as important as seeing them through an immediate crisis.
    - One example was given of evidence of the voice of the patient being listened to and changing practice – the inclusion of “itch” in Scottish Intercollegiate Guidelines Network (SIGN) psoriasis guidelines. The nature of the SIGN process meant that the patient voice was heard, and the guideline was changed, even where there was not clinician support for the change of guideline.
- PROMs should support a stronger sense of partnership between patient and professional. The patient can update the healthcare team on changes without needing to make another appointment. PROMs should help patients to feel that clinicians are approachable and want to support patients as individuals to lead their lives they way they want to, rather than purely as clinical cases.
- Patient buy-in and engagement to using PROMS is needed.
- Confirmation that everyone who needs support is being reached should be present– including all groups with protected characteristics.
- In the primary care context, evidence of “good” use of PROMS includes patient satisfaction – e.g. that use of PROMs enables more discussion of issues that matter to the patient.

What does a “good use of PROMs” look like? Cont.

Experience for healthcare professionals and outcomes for health services

- Improved experience for healthcare professionals and improved outcomes for the healthcare service as well as for patients is needed.
    - For example: reduction in clinician workload; time spent on consultations; reduction in escalations and unplanned admissions; effect on health resource use patterns; and early reporting of symptoms reducing escalation further down the line.
- Discussions noted a challenge in gathering evidence around reduction in clinician time spent on consultations. This needs manual audit which is time and resource intensive.
- It is important to engage with informatics and data analyst teams at the start of the PROMs project setup process to define what measures will be gathered to show impact.
- Qualitative measures of patient experience* are essential in addition to quantitative data.

*Patient Reported Experience Measures (PREMs) focus on the patients’ views of their experience while they are receiving care from a service. PROMs focus on patients’ feelings about their quality of life in relation to a health condition and/or treatment.

Breakout B: Getting past the pilot

What is needed during a PROMs pilot?

- Good data is important, as are clearly defined and agreed objectives / outcomes. The metrics of these should be agreed from the start of any PROMs project. Pilots should test a decision in principle and have a clear purpose.
  - It may be needed to hone-in on essential versus desirable outcomes to keep things achievable, taking a stepped approach, as necessary.
  - There may be trade-offs between patient versus service-level outcomes at first.
- Outputs and outcomes from PROMs projects should be clearly described at the end of the pilot, with lessons learned and recommendations.
- The pilot needs to have a positive impact on clinicians' time.
- The whole team needs to be "bought in". This includes front-line, managerial (up to Executive level) and planning staff, as well as patients etc.
- Involvement from Implementation Scientists and Health Economist may also be needed during pilots.
- Any new pilots should not start from scratch. There needs to be a clear articulation of what has been learned from pilots that have already been done, and how the next pilot will build on that and further progress towards overall agreed ambition(s).

What helps PROMs projects to get past the pilot stage?:

- An agreed and clearly described long-term national vision (i.e. 5-10 years from now) should allow local teams to design and deliver PROMs projects, with the SC PROMs Toolkit providing the framework for all local work.
- Early involvement from Health Economists in understanding the potential value of PROMs may help to ensure an appropriate approach to evaluation and measurement.
  - E.g. More than 80,000 PROMs forms have been completed at the NHS Christie, but the health economics case for PROMs could be strengthened due to level of variation being considered.

Getting past the pilot cont.

- Understanding how PROMs can help with service “pain points” is important.
    - For example, if services are stretched or safe / comprehensive patient assessments are not taking place, can PROMs release staff to help do more remote patient assessments where appropriate?
    - PROMs pilots can mean more work for staff. This has made pain points worse in the past. This may be because of lack of trust or understanding of the process etc.
- An interactive / searchable database of existing / previous PROMs pilots with outputs, outcomes and lessons learned would be helpful, with contact details of the people involved.

<u>What might get in the way of PROMs projects getting past the pilot stage?:</u>

- Knowing there are existing, or planned, PROMs pilots may create a lack of activity from teams.
    - People need to be able to learn, innovate and add value all the time.
    - Widespread buy-in for big national PROMs projects, or PROMs happening at a distance, is unlikely. Local work is needed to engage clinical teams and patients in change.
    - Local teams should encourage colleagues to get involved in existing pilots, supporting further implementations and/or making sure the local community is ready for anything coming in the future.
- A balance needs to be struck with respect to scale.
    - Work must be realistic around what can be achieved with the resources available. A stepped approach may help bring about the resources needed for next step (i.e. people may need to start small with very focused staff group and then expand the PROMs project as work progresses).
- Off-the-shelf PROMs offers typically fail because of lack of design involvement from people who will actually be “doing” PROMs. Also, there is often no clear objective for ongoing implementation from the start. Services should be clear about what they want to achieve from the start, and the chosen approach and what’s needed from the technology should be set against those objectives.

Breakout C: Beyond the patient information leaflet

Digital technology

- Ensuring technology is accessible is key to making sure everyone who wants to complete PROMs can do so, but also not stereotyping certain groups (e.g. “the elderly do not engage with digital tools”; many studies have shown this is not the case).
- While accessibility is crucial, PROMs tools being useful to patients as part of their care is arguably more important for long term engagement. For a long time, we’ve talked about digital exclusion but many patients who are happy to do a questionnaire just don’t do it because they don’t see the benefit for managing their own care day-to-day.
- PROMs may help patients / carers communicate their needs with clinical teams when face-to-face communication is difficult, time-restricted or feels confrontational.
- Patient perspective: “I don't want AI advice; I want more personalised responses”.
- We need to clearly define how to engage with non-responders (e.g. asking patient navigators to call patients etc.).

Improving patient uptake

- Establishing an “onboarding” model is very useful to get patients engaged from the start. This would include:
    - Pre-warning patients that they will receive a PROMs questionnaire (reassuring them that this is not “spam”).
    - Informing patients on why their data is being collected and how it will impact their clinical care.

Beyond the patient information leaflet cont.

  - Showing patients how they can visualise their own data to keep track of their health (if a patient-facing platform is available to allow them to do this).
  - Explaining how their information might be escalated and acted upon (e.g. in remote monitoring cases where the patient reports concerning symptoms, what happens next).
  - Reassuring patients about data security and who will have access to it (and in simple terms, not regulatory jargon like “GDPR”).
- Increasing trust through the service around the PROMs (e.g. all worrying symptoms will be dealt with within a set amount of time).
- PROMs can improve transparency and help to build trust between patients and clinicians through:
  - Shared decision making.
  - Improving clarity around why and how their data are being used.

<u>Patient education</u>

- Showing patients their PROMs scores (during consultations or through a patient-facing platform) can be helpful and motivating, ultimately improving patient engagement with their health and increasing “health literacy” (i.e. the ability to understand and use health information to make informed decisions).
  - The potential downside is “knowing” too much and not being able to interpret abnormal results, causing anxiety or increased contact with services.
- Helping patients (and their clinicians) interpret their PROMs scores is gold standard (e.g. how has the trend changed over time and what this could mean for treatment or self-management).
- Patient perspective: “don’t set yourself a target, notice the trend”.

Beyond the patient information leaflet cont..

Potential barriers

- The patient may feel, “What is the point of doing this? I prefer to call my Clinical Nurse Specialist”:
    - There is patient anxiety about digital technologies and AI, which can be fuelled by what they see in the media.
- If questions are not simple or are “suggestive” (e.g. “are you struggling with daily tasks”), it might reduce the patient’s likelihood to engage with the questionnaire. However, if patients are asked directly (e.g. “can you cook your own meals”), less triggered responses might result.

Patient concerns

- Patients may be worried if they record that they feel depressed that it will affect their private insurance or other aspects of their care.
- Patients may not report experiencing symptoms of medication toxicity or serious side effects out of fear of their treatment being withdrawn.
- Automations and AI responses may not be context-specific:
    - For example, a patient may report having shortness of breath and may be advised to see their doctor despite this being a known chronic condition for that patient already.

Q&A Content

Here we have included a summary of the questions and answers posted in the Q&A during the event.

Question: "Some side effects are described as "long term' and some of these are actually life long - so how are these followed up if at all? And do PROMS have a party to play here? i.e. once cancer patients are discharged from treatment & maybe self-managing these kind of side effects in the community, who keeps an eye out for them?"

Question: "Could the following phrases be outlawed completely and replaced by words which mean something to non-governmental, non-medical folks: *Health Literacy, Patient onboarding* and *Dashboards – Health Literacy* makes most ordinary people feel as if a judgement has been made on them and not a very good one. Maybe a bit more effort needs to be made to use language we can easily take."

Question: "What happens to people who can't use mobile phones or computers, can't afford them or who don't have access to either? For example, I have a mobile phone but even with the largest font available to me I can't fill in things like questionnaires this."

Question: "Is the patient facing interface using the existing Right Decision Service App?"

Answer: "PROMS questionnaires that support the 7-step process are at Questions to prepare for my medicines review (PROMs) | Right Decisions"

Question: Could someone elaborate more on polypharmacy PROMs?

Answer: "https://rightdecisions.scot.nhs.uk/antidepressants-quality-prescribing-a-guide-for-improvement/polypharmacy-7-steps-process/ (after step 1 you can see the PROMs example)."

Question: "With the PROMs builder, are you going to utilise more validated PROMs or allow teams to create custom PROs tailored to their needs?"

Answer: "There is the technical capability to create own PROMs, however we will need to work with our Steering Group to put in place a governance and QA process around this."

Chat Content

Here we have included a summary of the comments and insights from the chat.

Acronyms used in discussions:

- Patient-Reported Experience Measures (PREMs) gather information on patients' views of their experience while they are receiving care.
- PID = A Project Initiation Document is essentially a project brief, outlining the key aspects of a project, including its purpose, scope, goals, stakeholders, and deliverables, serving as a roadmap for project execution.
- NES = NHS Education Scotland.
- QALYs = Quality-Adjusted Life Years, a measure of health outcomes that combine the length of life with the quality of life, used to assess the value of medical interventions in economic evaluations.

Links, comments and other questions

- Link to the PROMs Toolkit: Patient Reported Outcome Measures: A toolkit to measure outcomes that matter | Turas | Learn
- Link to previous SC PROMs Forum Event reports: GGC Medicines: Publications
- Comment: “Wondering about the development of AI and also the potential classification of medical device status?”
- Comment: “I didn't manage to cover every point raised in our group (Breakout A). The point about equity and inclusion reminds me that a key measure of success raised in our discussions was access by all equalities groups, e.g. taking account of age, digital literacy, ethnicity, language etc.”

What Next?

- The Scottish Cancer PROMs Advisory Group will take the information in this report to:
    - Support the use of the SC PROMs Toolkit
    - Inform future versions of the toolkit
    - Understand what other support can be offered to PROMs implementers in Scotland
    - Understand what other support can be offered to patients and their families and carers in relation to the use of PROMs in practice in Scotland.

- This report will be shared with the Scottish Cancer PROMs Advisory Group and all those who registered for this SC PROMs Forum Event.

- This report will also be shared with the Scottish Cancer Strategic Board at Scottish Government. This is who the Scottish Cancer PROMs Advisory Group reports to.

Presenter Biographies

& Dr Ann Wales (Programme Lead, Knowledge and Decision Support, NHS Healthcare Improvement Scotland)

Ann is national Programme Lead for Knowledge and Decision Support, based in NHS Healthcare Improvement Scotland. She leads the national decision support programme funded by Scottish Government Digital Health and Care and promotes methods for mobilising knowledge to improve health and care services. The cornerstone of this programme is the Right Decision Service - a 'Once for Scotland' source of digital tools that bring evidence to the fingertips of professionals and citizens through day-to-day technology such as web and mobile apps and embedding in electronic care systems.

Prior to taking up this post, Ann held national roles in knowledge management, digital development and decision support in Scottish Government and the Digital Health & Care Innovation Centre. She also led national development of knowledge strategy for health and social care and digital knowledge services as Programme Director for Knowledge Management within NHS Education for Scotland.

The driving force behind Ann's work is fusing digital technology and knowledge to embed evidence into day-to-day practice across health and care.

Dr Stephen Martin (Realistic Medicine Policy Team, Scottish Government)

Stephen Martin is the Realistic Medicine Team Leader in the Scottish Government. He is part of the team that is responsible for Realistic Medicine and Value Based Health & Care policy. An important element of that remit is to support coordination of a national approach to the delivery of PROMs in Scotland.

Dr Thitikorn Nuamek (Pao) - Clinical Research Fellow – ePROMs, The Christie NHS Foundation Trust, Manchester

Dr Thitikorn Nuamek (Pao) is a Clinical Research Fellows in ePROMs at The Christie. Originally from Thailand, he holds a first-class medical degree from Romania and has hospital training experience across four continents. He has an unwavering passion for advancing healthcare through technology and patient-centred research. In his current position, Pao plays a pivotal role in driving the trust-wide implementation of ePROMs and actively contributes to education and research initiatives. Beyond this, he is the Technology Lead for UK Early-Career Researchers in Cancer (UK ECRC) and British Oncology Network for Undergraduate Societies (BONUS), developing a first-of-its-kind mobile app 'BONUS Official,' dedicated to education in cancer care.

SC PROMs AG Executive Team

Peter Hall - *Reader and Consultant Medical Oncologist, Edinburgh Cancer Research Centre, University of Edinburgh; Edinburgh Health Economics Group Lead, Edinburgh Clinical Trials Unit & Co-Chair of the Scottish Cancer PROMs Advisory Group*

Peter is an academic Medical Oncologist with a research interest in Health Economics, Data Science and Health Technology Assessment in Cancer. The focus of his research is on the development of improved methods for efficient research design, cost-effectiveness analysis and the measurement of clinical and socioeconomic outcomes using data obtained from clinical trials and routinely collected within health systems. He leads the Edinburgh Cancer Informatics Programme which provides healthcare data analytical capabilities for both NHS Cancer Services in South East Scotland and the CRUK Scotland Centre's research programmes. He treats patients with breast cancer within the NHS at the Edinburgh Cancer Centre..

Emma Dunlop - *Research Fellow, Strathclyde Institute of Pharmacy & Biomedical Sciences, University of Strathclyde & Co-Chair of the Scottish Cancer PROMs Advisory Group*

Emma is a researcher in the Pharmacoepidemiology & Health Care Research Group at the University of Strathclyde. She works on the Scottish Government-funded Cancer Medicines Outcomes Programme-Public Health Scotland (CMOP-PHS); a national collaboration between the University of Strathclyde, NHS Boards and Public Health Scotland. The main aim of CMOP-PHS is to understand the real-world impact of cancer medicines on patients in Scotland. Emma is also passionate and active about patient and public involvement.

Debbie Provan - *Clinical Advisor, Cancer & Rehabilitation Unit, Scottish Government*

Debbie is a Clinical Advisor to the Scottish Government's Cancer and Rehabilitation Unit. She is responsible for a number of actions within the current Cancer Action Plan and 10-year Cancer Strategy, including those which focus on prehabilitation, single point of contact and patient reported outcome measures (PROMs). With a background in Dietetics, she has worked in cancer services for a number of years, spending a significant time supporting the delivery of Scotland's Transforming Cancer Care Programme through Regional Clinical Lead and National AHP Lead roles.

Kevin Gallagher - *Specialist Trainee in Urological Surgery, NHS Lothian & Fellow for Data Driven Innovation, Clinical Lecturer, Public Health Scotland*

Kevin is a Specialist Trainee in Urological Surgery, Academic Clinical Lecturer in Urology at the Cancer Informatics Group, University of Edinburgh and Clinical Fellow for Data Driven Innovation with the Centre for Sustainable Delivery / Public Health Scotland. Kevin has an interest in using real world healthcare data more effectively for quality improvement and incorporating patient reported outcome measures in this. Kevin leads a national programme collecting patient reported outcome measures after prostate cancer treatment. He also leads a global cluster randomised controlled trial testing a digital performance feedback intervention to improve quality in bladder cancer surgery.

This report of the SC PROMs Forum event was written by the SC PROMs Forum & Advisory Group Executive Team, with thanks to the Cancer Medicines Outcomes Programme-Public Health Scotland Patient Representative for their contribution.
Thank you to the breakout facilitators, whose notes formed a key part of this report.

Emma Dunlop- Co-Chair of the SC PROMs AG, Research Associate, Cancer Medicines Outcomes Programme, University of Strathclyde
Peter Hall- Co-Chair of the SC PROMs AG, Academic Medical Oncologist, University of Edinburgh
Debbie Provan- Clinical Advisor - Cancer Policy, Scottish Government
Kevin Gallagher- Specialist Trainee in Urological Surgery, NHS Lothian & Fellow for Data Driven Innovation, Clinical Lecturer, Public Health Scotland

To find out more about the Forum or Advisory Group, please contact PHS.CMOP@phs.scot

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