Scottish Quality Registry for Rheumatology (ScotQR)

Evaluation of Pilot

July 2020
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1. Executive Summary

Scottish Quality Registry (ScotQR) for Rheumatology piloted a “real time” quality registry in clinics for patients with Rheumatoid Arthritis as a ‘learning health system’ to facilitate:

- shared-decision making during clinical consultations
- recording of Patient Reported Outcome Measures to support co-production of care
- self-management
- symptom tracking
- Collaborative improvement opportunities across sites.

Healthcare Improvement Scotland received funding from the Health Foundation, to pilot ScotQR in NHS Lanarkshire and NHS Greater Glasgow and Clyde. The pilot took place from October 2019 until March 2020. Collaboration between clinicians, patients and Cohesion Medical (digital provider), was central to the design and development of ScotQR.

Data was collected from 16 clinics where a total of 101 patients were asked to participate, with 92% of people agreeing. Key evaluation findings:

- CollaboRATE questionnaire assessed the degree to which patients felt they were involved in the decision making process during their outpatient appointments
  - Pre pilot CollaboRATE Scores: 78% scored 9 in all domains
  - Pilot CollaboRATE Scores: 93% scored 9 in all domains

- Qualitative interviews with patients evidenced:
  - 95% of patients were positive about using the registry
  - 68% felt that it helped them to remember what to raise during the consultation
  - 89% indicated they would be willing to try using ScotQR at home and patients post pilot have expressed a desire to see ScotQR continued

Further adoption of ScotQR across Scotland will offer immediate benefits to patient care through:

- the ability for patients to report and record their own assessment of their disease
- responsive services for physically isolated patients during and after COVID-19
- improved shared decision-making and co-produced care management
- supported self-management and improved health literacy
- reduced waiting times by prioritising patients most in need
- work disability screening.
Further adoption in the medium to long-term would provide a fuller picture of benefits of the system and data collection over time (for example more effective prescribing, reduction in disease burden, evidence to support service improvement).

Partner organisations are seeking support to extend use of ScotQR, including continuation in the pilot sites, testing of the system in other boards and, if successful, extension across Scotland for rheumatology.

2. Introduction

Inflammatory arthritis places a substantial burden on the healthcare system and reduces patients’ ability to remain in employment and enjoy a good quality of life: data from the British Society for Rheumatology indicates that 44,000 people in Scotland have a diagnosis of rheumatoid arthritis in 2018. This has resulted in biological treatment costs exceeding £42.75M pa. Many patients report difficulties accessing the information and resources they need to maintain their health. The Scottish Government has set out significant health priorities including having everyone ‘living longer and healthier lives at home or in a homely setting by 2020’. In order to meet this priority, there needs to be a significant transition in the way we implement health services going forward. Coproduction of healthcare, improvements in health literacy, and better integration of services are essential steps needed to achieve this vision.

In order to improve the quality of care provided to patients with inflammatory arthritis and ensure the cost-effective use of biological medicines in rheumatology we need to understand the complexities around the patients’ symptoms and long-term management strategies. There is poor reporting about the impact of biologics upon a patient’s overall health and about their effectiveness long-term, as current data sources are far from comprehensive. In a recent survey of Scottish Rheumatologists, 75% noted limited or no collection of accurate and detailed data about patient activity, diagnosis or outcomes.

Consistent data collection is crucial to developing services fit for purpose in today’s healthcare environment but is hampered by both technical difficulties and inadequate staffing capacity. Collection of real time data would allow us to understand patients better;

1 Rheumatology in Scotland: The State of Play, British Society for Rheumatology 2018 https://www.rheumatology.org.uk/Portals/0/Documents/Policy/Reports/BSR_State_Of_Play_Scotland_2018.pdf?ver=2019-03-11-094117-440 Anecdotal estimates by consultants suggest that the actual number of RA patients in Scotland could be between 60,000 and 75,000
4 Op Cit, The State of Play
allow improvements in shared decision-making; implement more effective resource allocation and develop a platform for future research.

This lack of data and indicators hinders demonstration of clinical outcomes or using performance information to improve care. It also limits the information about the use of resources that is available to healthcare planners and local managers and therefore impacts efforts to improve optimal delivery of care. Given the financial challenges that currently face the NHS, it is essential to demonstrate the benefits of delivering patient centred, effective and efficient care.

The importance of capturing patient reported outcomes has been noted in recommendations for service development for those with rheumatic disease in Scotland. Rheumatology teams face challenges providing optimal clinical management and very real prescribing and cost pressures. There is evidence that early effective care can improve outcomes and reduce work disability. Lack of effective outcome data has been highlighted as a major barrier to achieving the ambition of timely, effective, person-centred care. The Scottish Public Health Network recommends establishment of self-management programmes and screening for work disability alongside the establishment of disease registers and a national biologics database.

Learning health systems seek to support collaborative healthcare choices of patients and clinicians, generate new knowledge as an ongoing, natural by-product of the care experience, and facilitate improvements in quality, safety, and value. They harness the power of data and analytics to learn from every patient, and feed the knowledge of “what works best” back to clinicians, public health professionals, patients, and other stakeholders to create cycles of continuous improvement.

A quality-based registry enables person-centred and co-produced care management. This focuses on outcomes of patient wellbeing as well as validated clinical outcomes and a longitudinal record of disease management for individual patients that will encourage improved communication between patients and members of the clinical team; an essential component of true shared decision making. In addition, the aggregated data will provide local teams with information that can be used for benchmarking and evaluation of change. This tool will also support quality improvement initiatives and cost management. Quality registries have already achieved statistically significant improvements: in Sweden, where a

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50% reduction in the effects of disease was claimed among people with rheumatoid arthritis.

3. Piloting the Scottish Quality Registry

3.1 Partnership and Funding
The Scottish Rheumatology Quality Registry is a collaborative project that puts co-design between patients, clinicians and digital healthcare providers at its centre. Healthcare Improvement Scotland (HIS) has led the programme with support from the Scottish Society for Rheumatology (SSR), the Karolinska Institute in Sweden and the Dartmouth Institute in the USA. Patient input to the project was provided through the National Rheumatoid Arthritis Society (NRAS), Versus Arthritis, and patients attending clinics in the pilot sites. The Health Foundation funded registry development and implementation and the project was endorsed by the Chief Pharmaceutical Officer at the Scottish Government. Clinical and eHealth representatives undertook a study trip to Sweden at the beginning of the project – this provided an opportunity to view the importance of a well-established registry and its benefits at first hand.

3.2 Project co-ordination
Weekly teleconferences took place between the HIS project team and consultants from the pilot sites. There were also regular calls between the project team, Karolinska Institute (Sweden) and Dartmouth Healthcare in the US. These enabled sharing of ideas in relation to programme development and technology across health care systems. A steering group including clinical staff, academia and patient group met quarterly.

3.3 Digital Platform
The contract to develop the digital interface for the registry was awarded to Cohesion Medical, a UK based IT Development Company with experience in delivering innovative eHealth technologies. The registry was designed in partnership with patients and clinicians to ensure it was tailored to meet their needs. The registry went through extensive testing, and clinicians and Cohesion Medical provided training sessions for the programme team. The patient reported elements of the registry were designed to be completed by patients using IPads in the waiting rooms of rheumatology clinics and this information transferred to the clinician prior to their consultation.

3.4 Participants
Patients
Individuals with rheumatoid arthritis were recruited from two pilot sites (NHS Greater Glasgow and Clyde and NHS Lanarkshire). Patients were informed of the purpose of the

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registry and provided with a patient information sheet before giving informed consent. Those who agreed to participate were provided with an iPad tablet where they completed a series of questions about their condition in order to direct their consultation. On one site, a healthcare assistant provided help with accessing the questionnaires and putting at ease people less familiar with technology.

Consultants
Consultants had access to the patient reported data before and during consultation. Clinical assessments (DAS 28) were recorded along with drug therapy. A free text note section was completed with a brief summary of agreed actions. This is a key component of coproduction of care. Firstly it provides a platform for patient and consultant to co-assess health status; Secondly they can co-decide the next steps in the care plan based on the patient’s preferences, values, and goals; thirdly they co-design the care plan to fit the patient’s goals, context, and capabilities; and, fourthly they co-deliver self-care and professional services to achieve goals of care.

At the end of the consultation a summary pdf document was created and printed for the patient for self-management in between visits. This included a copy of the patient reported items, the clinical assessment, drug therapy and agreed actions. Three consultants participated in the pilot across both sites and were asked to comment on whether there were any issues in the implementation and overall management of the pilot, and whether there were any benefits and drawbacks through the consultation with the patient with the addition of the registry.

3.5 Measures
Musculoskeletal Health Questionnaire
The Musculoskeletal Health Questionnaire (MSK_HQ) was developed in 2016 to examine the key outcomes that patients with long-term conditions identified as most important. The MSK-HQ has undergone extensive psychometric testing including in a number of cohorts from community physiotherapy, and secondary care orthopaedic hip, knee and shoulder clinics. The authors found high levels of completion (94.2%) with excellent test-retest reliability and strong convergent validity (Correlations 0.81-0.88)\(^8\).

What Matters to You?
A national priority in Scotland is to put the patient at the heart of the consultation. The ‘What matters to you’ programme was developed to facilitate conversations between the patient and clinician and to ensure the consultation is focused towards the needs of the patient. For the purpose of this trial, phrases were developed by patient groups through a series of focus groups and consultations to understand what is important for rheumatoid arthritis patients.

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\(^8\) Development and initial cohort validation of the Arthritis Research UK Musculoskeletal Health Questionnaire (MSK-HQ) for use across musculoskeletal care pathways, Hill et al BMJ June 2016
https://bmjopen.bmj.com/content/bmjopen/6/8/e012331.full.pdf
Clinical Assessment
Clinical assessments recorded were DAS28, a measure of disease activity in rheumatoid arthritis. DAS stands for 'disease activity score' and the number 28 refers to the 28 joints that are examined in this assessment. Current drug treatment was also recorded.

Follow Up Telephone Calls
Following the clinic visit, patients received a follow-up call from a nurse where they were asked a number of open-ended questions to evaluate their experience of the registry. Patients were asked questions surrounding their overall impression of the registry, whether it helped to focus the consultation, and whether this is something they would be willing to complete in the future, either in clinic or between visits at home. Questions are included in Appendix 2.

Pilot feedback
Following the completion of the pilot, a number of individuals involved were invited to provide feedback on aspects of the pilot they felt went well, what could have been improved and what we could learn from it going forward.

4. Results
4.1 Overview
Data was collected from 16 clinics where a total of 101 patients were asked to participate. Over the course of the 12 weeks. 93 (92.1%) of patients invited, agreed to participate. Only six declined to participate, but seven who were agreeable were unable to participate due to a (now rectified) WiFi connection issues.

Demographic data was gathered for 96 (95%) participants. 78 (81%) of those were female and 18 (19%) male. The average age was 63.5 years. The youngest was 24 years old and the oldest 85. Age and gender is not included in the following data analysis. Demographic data has not been linked to people’s experience of using ScotQR.

The average time taken for patients to complete the ScotQR app was 9m 50s from start to end. On completing the app participants were given the option to rate their experience ‘How would you rate your experiences with the ScotQR app today?’ Feedback was provided by 76 people. 71 (93%) gave it 3 stars, 2 (3%) gave it 2 stars, 1 (1%) 1 star and 2 (3%) No stars.

4.2 Scores for the MSK-HQ
Musculoskeletal Health Questionnaire (MSK-HQ) data was collected in 86 individuals with a mean score of 23.9 (range 4-46). Fifty-four (61.4%) individuals scored ≤25.

On average it took 271secs or 4m 30s to complete MSK-HQ.
4.3 DAS 28 scores, Summary of Drug Therapies

DAS-28 data was collected in 83 individuals with a mean score of 3.6 (range 0.49-7.4). Scores were classified into current disease state. 39/46.9% were classed as having an inactive (≤3.2) disease status, 33/39.8% moderate (>3.2 but ≤5.1) and 11/13.3% very active (>5.1) disease status.

Multiple medications were prescribed to individuals with the most common being methotrexate (38 prescriptions); sulphasalazine (25 prescriptions) and hydroxychloroquine (23 prescriptions). The majority of participants with medication data (n=68) were prescribed only one medication (39/57.3%) with two medications in 21 (30.9%) and three medications prescribed in eight (11.7%) individuals.

4.4 What Matters to You?

Eighty-one individuals selected the ‘What Matters to You’ option within ScotQR to focus the discussion during the consultation. The top five areas selected were pain (38/46.9%); medication (33/38.0%); fatigue (32/36.6%); sleep (29/33.8%) and mobility (21/22.5%). 38% of participants selected only one option while 51% selected three or more areas. Only two of the 24 options were not picked at all, implying that the options gave a good spread.

4.5 CollaboRATE

As part of the pre-intervention work for the pilot, the degree to which patients felt they were involved in the decision making process during their outpatient appointments was assessed using the CollaboRATE questionnaire. CollaboRATE is an independently verified method for assessing the process of shared decision making and assesses three core SDM tasks: (1) explanation about health issues, (2) elicitation of patient preferences and (3) integration of patient preferences into decisions. Responses to each item range from 0 (no effort was made) to 9 (every effort was made). CollaboRATE scores are calculated as the proportion of participants who report a score of nine on each of the three CollaboRATE questions.

**Pre pilot CollaboRATE Scores:** We surveyed 68 consecutive patients, 53 of whom scored 9 in all domains (78%).

**Pilot CollaboRATE Scores:** We surveyed 42 consecutive patients, 39 of whom scored 9 in all domains (93%).

4.6 Qualitative Interviews

Of the 101 total participants, 31 (30.7%) patients were contacted via telephone for interviews to assess their experience of using the registry. Nineteen (61.3%) agreed to answer the questions. In question one, patients who completed the survey were overall positive about the registry (18/19). The responses ranged from “ok”; “good” to one participant who described it as “brilliant”. Despite the positive response, four patients felt that while they thought it was a good idea, they struggled with the technology and indicated

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that they required assistance when completing registry tool. Patients reported support from the healthcare assistant as being helpful. For example, a number of individuals reported feeling wary of using technology but felt better with support provided; even commenting that is was much simpler than they had thought.

Patients were asked whether they felt the registry was helpful in guiding some of the conversations within the consultation. Thirteen out of 19 individuals felt that it was, with some comments including “reminds them of what they might ask”; “used as a prompt”; “yes, wanted to ask something, mind goes blank, doctor can then prompt” and “yes, gives the doctor a heads up to the major problems”.

Patients are able to receive printed information from their consultation. There were issues at some of the early clinics with generation of the pdf so only about half of the patients were given this. Those who received it they found it beneficial, with one patient saying the “found the printout useful, and kept it as a reminder”.

A goal of the registry in the future is to allow patients the option to complete the pre-visit questionnaire at home in between clinic visits. Patients were asked whether this would be something they would like and 17 out of 19 indicated it would be something they would be willing to try. Two of the patients highlighted they would use it if they had IT help at home.

Currently patients have the option of calling a patient helpline for additional support in between clinic visits. Patients in the survey were asked if the registry would be something they would use instead of the helpline. Fourteen out of the 19 patients felt that they would be happy to use the registry instead of the helpline and 4/19 indicated that they would use both methods. One patient felt that it would “possibly be quicker this way” and another commenting on the reduced burden on staff saying, “it would make it easier for nursing staff who pick up the calls”. In the four patients who said they would not use it, they felt that “if bad flare they would phone for an appointment”.

4.7 Stakeholder Feedback

The healthcare assistant supporting patients, two rheumatology consultants, the patient representative on the ScotQR steering group, staff from Cohesion Medical and the eHealth representative on the ScotQR steering group all provided feedback. There were a number of positives to come out of the pilot. Firstly, patient engagement and enthusiasm for the registry. Secondly, the co-production between patients, clinicians, pharmacists and digital design team was felt to be a strength to the delivery of the project. Finally, regular communication between the team helped to facilitate cohesiveness and progress of the pilot.

Prior to commencement and throughout the duration, there were some common issues noted. Firstly, getting the pilot up and running at one of the sites due to delays in getting the necessary local IT support and then a re-focussing of the lead clinician’s role, meaning he was unavailable at the clinics to co-ordinate recruitment, and for the clinics themselves. Secondly, there were a number of instances where patients had to input their details more than once due to the IPads freezing. Finally, one site had no healthcare support, which
increased the burden on the consultant during the clinic, reducing overall time available to spend with patients.

From the patient perspective the registry created an important link between the patient and clinician, facilitating continuity of care. Clinicians felt it was, overall, a positive experience for patients and, with IT improvements and integration of support from a healthcare assistant, it would be a welcome addition to clinical practice going forward. The healthcare assistant felt the pilot was a success. It was highlighted that it was an essential step forward in the patient clinician interaction and, despite a few initial IT issues, it would be beneficial in the development of healthcare provision in the future.

5. Discussion

5.1 Strengths and Weaknesses
Success factors and weaknesses are discussed in more detail in Appendix 1.

Strengths

Pilot Results
- Development of ScotQR was well received and positively demonstrated the impact on shared decision making, person centred care, and ease of use by patients

Clinical Support
- Clinical leadership and willingness to overcoming barriers through a core belief in proof of concept
- Healthcare assistant being onsite to explain what ScotQR is about and put patients at ease with the technology

Collaboration
- Collaboration between patients, clinical staff, and Cohesion in designing ScotQR
- Collaboration at a strategic level between participating NHS boards, National Rheumatoid Arthritis Society, Healthcare Improvement Scotland, and NHS National Services Scotland enabled strategic co-ordination and learning
- Workshop (March 2018) for patients and clinical staff scoped issues and how these could be addressed by ScotQR and demonstrated enthusiasm by both to implementing this system
- Health Foundation and international collaborators were supportive and provided reassurance, advice, and encouragement throughout
- Field visit to Sweden to view an established disease registry for rheumatology validated the benefits and potential of implementing such a system in Scotland

IT Development
- Technical support from Cohesion to make improvements and fix software glitches was responsive and effective
Weaknesses

Staffing
- Medical leadership was unable to continue in one site due to delays in setting up followed by competing demands thus impacting on patient recruitment
- Discontinuity of programme management staff supporting the project
- Researcher analysing data and drafting the evaluation report did not have dedicated remit for the project

Information Governance
- Lengthy information governance approval process to enable transfer of data from pilot sites to safe haven then from safe haven to HIS researcher
- Transfer of quantitative data from safe haven was delayed due to technical issues

IT Development
- Poor technical support from NHS IT in one pilot site delayed recruitment of patients by weeks
- Commitment to strategic innovation by eHealth colleagues with a focus on immediate local problem solving
- Initial reliance on direct use of the Swedish system complicated by technical, communication and information governance issues

Pilot Length
- Long-term data on patient outcomes not possible within the limited time period of the pilot

5.2 Future Direction

We will promote the evaluation of ScotQR through the clinical community with a view to bringing about wider adoption across Scotland. ScotQR is being developed to support its use by patients from home and the benefits this brings are particularly important in supporting RA patients that are unable to attend clinics due to COVID-19. Even as lockdown eases this will continue to be an important mechanism in enabling patients /clinician interactions to happen remotely and support reductions in waiting times caused by clinic backlogs through prioritising patients with high disease activity and monitoring those who are more stable (“open/tight clinic concept”). Investment in ScotQR has the potential for cost savings through more effective use of treatments, service improvements, and wider socio/economic benefits such as maintaining people as economically active and reducing transport time and costs. This is in addition to increasing patient engagement and confidence in their ability to self-manage between visits, which can ultimately lead to better health and outcomes for people living with a rheumatic condition.

Healthcare Improvement Scotland has prepared a business case proposing adoption of ScotQR across Scotland using an incremental approach. This will require technical investment and support as well as of a national ‘learning system’ to facilitate exchange of practice and a cohesive approach to patient focus and system improvement.
We have engaged with Scottish Government to ensure ScotQR can be part of the development of national programmes, whilst also acknowledging there is scope for local progression at an accelerated pace in response to COVID-19. This dual approach allows incremental adoption, ensures close connection with the patient and clinical community, and also retains connection to national strategies and programmes.

6. Conclusion

The aim of the ScotQR pilot was to test the concept of a platform for shared decision-making to facilitate co-produced, person-centred care. This is central to the Chief Medical Officer’s Realistic Medicine strategy. The pilot demonstrated the benefits of ScotQR for patients and clinicians and a desire to see its continued use, including for patients to use it remotely. Further adoption of ScotQR across Scotland will offer immediate benefits to patient care:

- The ability for patients to report and record their own assessment of disease (Patient Reported Outcome Measures) that are then linked to clinical measures for the patient to give an assessment of their disease status
- Responsive services for physically isolated patients during and after COVID-19 pandemic through remote consultation and monitoring with synchronous /asynchronous appointments
- Improved shared decision-making and co-produced care management
- Supported self-management and improved health literacy
- Reduced waiting times by prioritising patients most in need
- Work disability screening

Partnership working between clinicians, patients and Cohesion was important locally and in providing a platform for the pilot boards to share learning and problem solve. Patients often needed support to get used to the technology and once they had used it felt comfortable with it.

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10 **Synchronous** means that you can only execute one thing at a time. **Asynchronous** means that you can execute multiple things at a time and you don’t have to finish executing the current thing in order to move on to next one.
ScotQR has a number of other significant benefits for patient care that have been evidenced from long term use in Sweden:

- Effective prescribing by understanding trends of drug use linked to clinical data
- Reduction in disease burden
- Providing data and evidence for service improvement

The Swedish registry has been evolving for over 25 years and the spread (over 90%) and power of the data is inspiring. Whilst we do not anticipate that it will take 25 years to deliver the same benefits in Scotland, the benefits realisation will be incremental and not immediate e.g. the impact on consultation and shared decision-making would be first, followed by longitudinal data on individual patients followed by service redesign and data on groups of patients and practice.
Appendix 1 - ScotQR Demonstration images

A short demonstrator video for ScotQR can be located at:
https://www.youtube.com/watch?v=ylSOVKCltsq&feature=youtu.be
Appendix 2- Discussion of Successes and Challenges

Field visit to Sweden
In October 2017 clinical staff conducted field study visit to Sweden to get demonstration of Swedish Quality Registry and representation of benefits. This identified the following benefits to patients in adoption the SQR model of care:

- Improving observation of medication changes and side effects
- Positive examples of shared decision making between patient and clinician in real time
- The facility to benchmark each County with the national sample in real time
- Understanding your service in comparison with others and therein the opportunity to identify Quality Improvement domains for action
- Effective prescribing by understanding trends of drug use linked to clinical data
- Allowing for reflection on practice
- Support for decision making on national procurement strategies
- The ability to identify all patients who had not been seen by the service for a year
- A dashboard facility to see at a glance patients 'doing badly' to trigger urgent review
- Considerable scope for research, including links with Scotland’s Biobank

Workshop
In March 2018, an event was hosted for patients and healthcare professionals to explore the benefits and challenges of using the ScotQR in the pilot sites, NHS Lanarkshire and NHS Greater Glasgow and Clyde. Forty healthcare professionals and patients attended the workshop. This identified what matters to patients, what currently works well in clinics, and ideas on how to make things better. It also explored ways to measure the impact of the ScotQR project, and the design of the pilot site testing. The enthusiasm for improvements the ScotQR can make to patient care and a willingness to co-design the pilot was evident in all participants. A patient survey undertaken in NHS Lanarkshire also demonstrated the desire of patients to have more information about their condition. Staff in one pilot site completed a 5 session mentoring programme in QI methodology as part of the preparation for the pilot.

Collaborative Working
The combination of clinical leadership, patient contribution and clinical informatics from the start was key to shaping and delivery of the project. Our clinical leads, Dr Elizabeth Murphy (NHS Lanarkshire) and Dr Martin Perry (NHS Greater Glasgow & Clyde) were part of the project group, and ensured the project maintained its aim. They played a key role in defining the information that was critical for clinicians to have access to and how the system should look and be used from a clinician’s perspective. They sourced the data and the patients who were potential pilot participants. This made identifying the data sources a simple process.
The patient representative on the project group was part of the National Rheumatoid Arthritis Society (NRAS) and head of the NRAS volunteer ambassador group in Scotland. This patient perspective was central in keeping focus on patient need, advising on patient engagement, and on system design. The representative was an active participant throughout. The project benefitted greatly from her insights, enthusiasm, vision and desire for change through her real life patient experience.

A successful outcome of the project was the international collaboration with Prof. Lindblad (Karolinska Institute) and Prof. Nelson (Dartmouth Institute for Health Policy & Clinical Practice). This collaborative working provided us with a great source of information, expertise and advice. This supported us to identify and apply the transferrable components of successful approaches from other healthcare systems. This relationship, developed from our clinical experts’ awareness of the Swedish system, dovetailed with the professional relationship our Medical Director and the international collaborators already had in place.

There a number of key policy documents that enabled this work to be understood and supported in Scotland e.g. Healthcare Improvement Scotland’s Quality Strategy, the Chief Medical Officer for Scotland’s last four Realistic Medicine annual reports, and the Scottish Government’s eHealth, digital, and health literacy strategies.

We should not underestimate the combined power of enthusiastic and committed patients who have innovative ideas and the will to carry them through. Keeping to the original concept of the intervention is an ongoing task to ensure that the work does not stray from the plan.

The enthusiasm of lead consultants to make a difference to patient care and national leadership within HIS has been important. Executive sponsorship within HIS to make a project happen is also crucial.

Digital Commissioning
We initially intended to use the digital platform used for the Swedish Registry through commissioning its host company, Carmona.

It was more difficult to collaborate across two very different health systems and, for reasons that are not clear, we were unable to establish the necessary details about the parts of the registry we would be able to access. In addition we came up against Information governance barriers in terms of data transfer out with the UK.

The IT system in Sweden was not transferable to the Scottish context due to the digital and IT infrastructure in the two countries being quite different. The Swedish registry has been embedded within the IT infrastructure for several decades whereas the digital maturity of the pilot sites was very different. If we were redoing this pilot we would move straight to commissioning a local system. We decided to commission a UK based IT developer, with
Cohesion Medical being awarded the systems development contract after a tendering process.

This stalled the momentum of the engagement of the stakeholders. This resulted in a degree of caution in re-engaging stakeholders as we needed the pilot data to demonstrate that the concept will work and deliver benefits for the patients and service. It seems to be a common experience of other countries that if there is a delay for any reason, it is hard to restart stakeholder engagement.

The fact that we endeavoured to complete the original plan but then had to commission IT development added a minimum of 6 months of delay to the project.

**Information Governance**

Information governance around the collection of patient data has been a major barrier and caused significant delays to the timeline. This was time consuming, complex and delayed the launch in pilot sites.

Information Governance requirements could have been considered more thoroughly during the scoping phase of the project. It proved difficult to work through what permissions were required, which colleagues needed to be involved and how the processes work. Changes to national Information Governance requirements within the project timeline added to the issue.

It is also questionable whether the Information Governance approvals we were asked to seek were necessary. Advice received after the establishment of the project has been that they were not and that an unnecessarily extreme position may have been taken by the NHS organisations involved as a precautionary measure against breaching GDPR regulations.

**Staffing**

The team experienced issues with the continuity of the programme management resource. This type of role relies on a dynamic workforce and the frequent changeover of programme managers created continuity issues and set us back several times throughout the project. We needed small amounts of expertise which we tried to secure from one individual which would have been better secured in a more flexible way through “days” of resource. This type of resource is however much more difficult to secure and build a team around. For future projects it would help to understand more fully and transparently the skill set required to support the project at every level and throughout the whole project.

In addition to programme management resource we needed more consistent input of quality improvement expertise. We also would have benefitted from having more junior staff to support the project for tasks such as organising meetings/events, drafting project documentation and project tracking. We also may have benefitted from having more input from project team members with expertise in eHealth and research, as well as external information governance expertise in the initial phase of the project to resolve data access issues and support the development of the project scope. This directly impacted on the efficiency and delivery of our work.
Once the pilots began to run there were evident advantages to having healthcare staff on site to support recruitment of patients, explaining the registry and using the i-pads. In NHS Lanarkshire a healthcare assistant was on hand to support patients. A short explainer/help video to introduce, LiveHelp support for patients and step-thru what to do before they used the webapp can also be used to support patients in future.

Limitations on Supporting Innovation
The NHS states that they are committed to innovation but some of the systems did not aid the innovation process. Influencing local eHealth teams could be challenging due to local priorities to maintain/replace basic systems and keep the essentials running, limited capacity for innovation, and perhaps less of an understanding of the policies related to strategic improvement in clinical and service provision. Influencing eHealth strategically is equally challenging due to the breadth of the agenda and getting the timing right to engage.

The pilot in NHS Greater Glasgow and Clyde experienced technical challenges that ought to have been straightforward to resolve but delayed commencement by weeks. Firstly the i-pads for patients to input data to the registry were not delivered and secondly, once delivered, there was no Wi-Fi signal within the clinic that would allow people to use the i-pads. Even though the lead consultant and HIS Programme Manager put considerable effort into chasing NHS Greater Glasgow and Clyde eHealth and IT colleagues to resolve these simple problems this held things up by around eight weeks. Consequently the patient numbers recruited in this site were very limited.

Appendix 3 - Follow up telephone call for Registry.
1. What is your overall impression of using the questionnaire and the registry tool in your recent consultation?
2. Follow up questions - explore in more depth- eg. if favourable – what was good? Did you find completing the questionnaire helpful prior to consultation?
   If no – could it have been improved?
3. Did you think the questionnaire and registry tool helped you to discuss the issues which you hoped to cover in the consultation?
4. Were there any things that you felt able to discuss that you would not previously have spoken to your doctor about?
5. Was the printed information you were given to take away after the clinic visit useful?
   How could it have been better?
6. Would you be happy to complete this type of questionnaire in between your clinic visits to help to monitor your illness?
7. If you could use the registry tool to contact the Rheumatology team between appointments, would you use this instead of phoning the helpline?
8. Is there anything else you would like to add?
Published Month Year

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