



AOANJRR

Australian
Orthopaedic
Association
National
Joint
Replacement
Registry

VAHI – AOANJRR Project: Optimising Feedback of PROMs Data to Patients in the Setting of COVID19-related Restrictions

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1. Executive summary

The overarching aim of VAHI-AOANJRR Project was to develop an understanding of consumer interaction with online health information and improve health information delivery. With the added complexities of COVID-19 impacting how consumers could access health information in the last year, the project aimed to assess whether community approaches to accessing health information changed, including their willingness to engage with more contemporary modes of delivering health information such as patient health information dashboards.

A literature review on international best practice examples provided the theoretical basis for working with consumer representatives to assess how The Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR) and its Patient Reported Outcome Measures (PROMs) online dashboards could better communicate health information to consumers. The literature review identified that for consumers to make use of their PROMs data, their needs must be considered for design, content and delivery.

Qualitative data was then collected at consumer engagement workshops which confirmed this finding. Data collected from the workshops demonstrated that consumers heavily depend on accessing health information via digital sources, second only in importance after medical practitioners. Accessing health information in this way comes with a series of challenges: relevant health information is difficult to find and often does not meet the needs of lay consumers. While producing adequate information that is written with consumers in mind can help fill the information gap, additionally providing consumers the ability to review their PROMs via an online platform can support them in their decision making around their health.

This report presents an analysis of key findings from both the literature review and consumer engagement workshops. The recommendations listed below and best practice principles found in the Conclusion provide guidance for overcoming the key challenges identified in the research, and can be adapted across a broad range of consumer-centred online health information resources.

1.1. Key findings of consumer engagement workshops

The key findings of the consumer representative workshops can be categorised into five main themes, summarised below:

1. **Consumer representatives source health information from three key areas:**
 - Health practitioner
 - Online via general search engines and specific trusted websites
 - Their families, friends and networks
2. **Health information currently does not meet consumer needs:**
 - Does not provide adequate information to assist with decision making
 - Is difficult to understand, more so for diverse populations
 - Is overwhelming in volume
 - Contradicts with other sources
 - Is not nuanced enough to assist consumers with needs that differ from the general population
 - Is deemed to be biased

- Is not designed, written or delivered with lay consumers in mind
 - Is often difficult to find
3. **Consumers need health information to be more comprehensive, relevant and written for lay audiences:**
- Information is independent, trustworthy, and unbiased
 - Copy meets Grade 8 reading level
 - Supports consumers at every stage of their health journey: from the start of the disease to recovery and long-term care
 - Presents all options for treatment
 - Helps consumers make informed decisions about their health in partnership with their health practitioner
4. **COVID-19 related restrictions have not altered consumer behaviour:**
- Consumers were well versed and practiced in accessing online sources of information
 - There was a slight increase in use of telehealth after the pandemic
 - o Although restrictions impacted the frequency of telehealth use, face-to-face consultations are still the preferred method for engaging with health practitioners moving forward
5. **Patient dashboards and online PROMs health information should be co-designed with consumers:**
- Only include information that is most relevant to consumers
 - o What the change has been in their pain and discomfort pre to post treatment
 - o How well they can use the affected body part e.g. joint
 - o Change in mobility and ability to undertake their usual activities
 - Include information about how consumers compare with others like them (if possible)
 - Provide simple information with the options to review more detailed data
 - Be mindful of navigation: this should be easy, interactive, intuitive and clean
 - Include elements that help with understanding information and results: bold colours that are meaningful (red = worse, green = better), infographics, explanatory text
 - Include an option to print the most relevant information e.g. patient health report
 - Include additional resources for assisting in decision making around health and procedures
 - Include information on national statistics that is available to all consumers well ahead of making any health decisions

The main findings from the consumer workshops are further outlined in detail in this report in Sections 9 and 10. These project findings are broad in scope and provide both VAHI and the AOANJRR with a solid foundation for improving the dissemination of health information to patients.

1.2. Recommendations for consumer engagement with online health information

The recommendations listed below have been derived from the consumer engagement workshops and can be adapted for use by the AOANJRR and other health information providers.

Accessing health information

1	Strengthen surgeon engagement and share targeted consumer information through surgeons and other health practitioners
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2	Increase consumer engagement with government health information websites and increase awareness of available information and websites
3	Create a guide for patients for navigating health services e.g. 'my joint replacement journey'
4	Create communication and engagement strategy targeted towards patients
5	Keep audience in mind when producing health information <ul style="list-style-type: none"> - Co-design health information with consumers - Increase consultation with diverse communities when creating new health information resources - Produce information that is comprehensive and includes important information for decision making (e.g. information on adverse events, success rates of treatment, how to set realistic expectations, and all treatment options) - Don't include jargon or acronyms
6	Produce information for families and carers
7	Continue to offer telehealth, however, this should be an additional option on top of face-to-face
8	Invest in digital platforms to support increasing consumer dependence on and preference for accessing health information via digital sources

Delivering health information via patient PROMs dashboards

9	Prioritise presenting health information that relates to the specific patient <ul style="list-style-type: none"> - Present specific patient-level information first (e.g. how much change there has been since treatment), then branch out to how they compare with others like them
10	Keep layout and design of information as simple as possible <ul style="list-style-type: none"> - Show simple statistics <ul style="list-style-type: none"> o Have option to view more complex/granular data for those who are interested - Explain key information through simple infographics and pictures - Use simple graphs to portray information and progress - Use simple and lay language, and avoid using acronyms and jargon - Make all pages and key results available for download and print <ul style="list-style-type: none"> o Suggested to add a downloadable summary report - Create dashboards that work across a range of electronic devices (computer, tablet, smartphone, etc.) - Group results by theme <ul style="list-style-type: none"> o This helps to simplify the layout - Use bold colours to help explain results (e.g. red indicates worse, green indicates better) - Adhere to visual impairment guidelines - Provide a search option should so patients can directly access information they are most interested in
11	Make information publicly available and easy to find
12	Provide supporting information, such as:

	<ul style="list-style-type: none"> - Information on post-surgery care - Testimonials from other patients - Questions for patients to ask their surgeon at their consultation - Information on the success rate of prostheses and arthroplasty techniques - Support in accessing allied health services - Information for carers - A resource such as a 'joint replacement journey handbook' that could cover topics such as what is a joint replacement, how to prepare for a joint replacement, how to take care of health after the joint replacement, what happens when it is time to leave hospital, how to make the most out of rehabilitation, and a guided joint replacement care plan - Additional sources of information and trusted websites, and a description of how these can assist in the patients' joint replacement journey
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2. Background

The Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR) collects data on all arthroplasty procedures which occur in Australia. It was established in 1999 and achieved full national implementation in 2002. The main purpose of the AOANJRR is to improve the outcomes of patients undergoing joint replacement surgery in Australia.

In October 2017 the AOANJRR established a pilot project to test the feasibility of the Registry collecting Patient Reported Outcome Measures (PROMs) from patients undergoing hip, knee and shoulder replacement surgery in Australia. A total of 45 hospitals participated in the pilot and over 12,000 patients consented to participate.

A key element of the PROMs Pilot was the launch of the data capture platform *RAPID* (Real-time Automated Platform for Integrated Data capture). The platform has the ability to obtain user consent, capture patient responses, integrate with existing AOANJRR ICT systems, and report data in real time back to all stakeholders including patients. *RAPID* is also flexible and modifiable, and future plans for the platform include exploring new ways to present data via online dashboards for diverse stakeholders and ensuring that any future patient reporting developments on the platform are guided by consumers.

The Victorian Agency for Health Information (VAHI) contributed to the AOANJRR PROMs Pilot and four Victorian Public Hospitals participated. In March 2020, VAHI approached AOANJRR to partner on a project that assesses the optimal methods for delivering PROMs feedback to patients and using *RAPID* to help patients engage with health information.

With the arrival of the COVID-19 pandemic in Australia came a change in approach to delivery of health services. This prompted a shift in the scope of the VAHI – AOANJRR Project to gain an understanding of how these changes impacted populations needing health information, and particularly for the more vulnerable communities such as the elderly. This is also of particular interest to the AOANJRR as the majority of patients who require joint replacements are elderly.

The VAHI – AOANJRR Project aims to obtain a better understanding of how patients interact health information, where there are gaps in both content and delivery of health information, if and how attitudes and behaviours in accessing health information have changed since COVID19

restrictions were implemented in early 2020, and how to best deliver health information via patient dashboards such as those that have been developed in *RAPID*.

3. Introduction

A patient reported outcome is defined as any report of a patient's health status that comes directly from the patient without interpretation by others (1). The purpose and objective of the AOANJRR collecting PROMs is to gain a greater understanding of patient health, quality of life and functioning prior to and following their joint replacement procedure and to provide this information to stakeholders who can improve the quality and cost-effectiveness of health care delivery. The AOANJRR's PROMs collection platform, *RAPID*, also delivers data directly back to patients so they can view their responses and understand how they have improved post-operatively as well as being able to view their health status in comparison to national averages. These dashboards provide an opportunity for patients to meaningfully engage with their data. Designing user-centred patient dashboards is dependent on understanding how consumers interact with health information, what type of information they need, and how to best design and format information for them. This has been recognised as an important objective by both the AOANJRR as well as VAHI and provides the impetus for this project.

In addition, the COVID-19 pandemic and related changes in both delivery and consumption of health information provides an additional opportunity for understanding how to best deliver information in a way that will be most useful for patients. Lessons learned from the pandemic can help the healthcare sector be better prepared in relation to infrastructure and policy so that health services and information can support diverse Australian communities now and in the future.

4. Aims of the VAHI-AOANJRR Project

4.1. Purpose and objectives

The goal of the VAHI – AOANJRR Project was to develop an understanding of how consumers interact with online health information. Specifically, the project sought to explore how consumer interaction with health information had changed due to COVID-19 impacts, how health information can be best communicated to consumers, and how patient dashboards can be used to provide meaningful and accessible health information to patients.

The objectives of the VAHI – AOANJRR Project were to:

1. Gain an understanding of the key traits of good consumer engagement with PROMs data.
2. Develop best practice principles for sharing PROMs data with consumers.
3. Gain an understanding of consumer engagement with online health information and the impact of COVID-19 restrictions on consumer access.
4. Develop recommendations for consumer engagement with health information post COVID-19.

5. Governance

A small agile management group (listed below) was established to guide the VAHI – AOANJRR Project. Group members were selected for their relevant PROMs and healthcare expertise and included members from the AOANJRR, VAHI as well as Associate Professor Ilana Ackerman from the School of Public Health and Preventive Medicine at Monash University.

The management group assisted with the preparation and review of documents, consumer recruitment opportunities, development of the discussion guides for the co-design workshops, and interpretation of consumer responses which informed the final recommendations.

Management Group Member	Position
Stephen Graves	Director AOANJRR
Louise Kelly	Acting Manager, VAHI
Ilana Ackerman	Associate Professor, Monash University
Cindy Turner	Manager AOANJRR
Grace O'Donohue	Project Manager, AOANJRR
Marta Jasińska	Project Coordinator, AOANJRR
Benedict Okonjo	Project Coordinator, AOANJRR

6. Study approvals

The VAHI – AOANJRR Project Protocol was approved by the University of South Australia's Human Research Ethics Committee.

7. Consent

The consumer co-design portion of the VAHI – AOANJRR Project used an informed opt-in consent model (see Appendix 6). Consumer representatives were provided with a study information sheet to sign prior to participating in the workshops.

8. Methodology

The project comprised of two stages, the first being a literature review (see Appendix 3). The aim of the literature review was to identify and learn from international examples of best practice for PROMs reporting and identify the fundamental strengths of PROMs systems around the world and their approach to engaging with patients. The literature review found that user-centred designed dashboards are important for promoting engagement with PROMs data and informed the second stage of the VAHI – AOANJRR Project and the co-design workshops.

The second stage of the project involved the team at the AOANJRR running a mix of face-to-face and web conference workshops with consumer representatives across South Australia, Victoria and New South Wales. The aim of the workshops was to develop an understanding of how

consumers engaged with health information and to use their input to guide refinement of the AOANJRR patient PROMs dashboards.

8.1. Literature review

A comprehensive literature review and examination of case studies was undertaken. The literature review provided the theoretical background required to examine a range of examples of PROMs dashboards. International case studies covering national, hospital and registry uses of PROMs were analysed to establish common traits of the most successful PROMs programs. Specifically, a study of the systems for patient completion of PROMs, patient feedback reports and clinician feedback reports concluded with the following recommendations for the further development of AOANJRR patient PROMs dashboards:

- a) Increase clinician training on the functions of PROMs data to increase usage and value in consultations.
- b) Review patient follow up timelines and post operation communication methods.
- c) Redesign the patient feedback reporting dashboard to better engage patients.
- d) Liaise with clinicians to build a system that allows online communication between clinician and patient regarding PROMs data.
- e) Generate supplementary information for the PROMs program on uses of the data for patients and clinicians.
- f) Design a tool for hospitals and providers to understand role of PROMs and aid practical implementation in their systems.

These findings informed the design of the consumer representative co-design workshops. The literature review was provided to consumer representatives ahead of the first workshop to help familiarise participants with the topic, and the international PROMs best practice examples were presented to and discussed with consumer representatives in the first of three workshops with each group. The examples of patient PROMs dashboards provided a baseline for workshop discussion guides (see Appendix 4). Consumer representatives then had the opportunity to discuss what they liked about each PROMs example and propose what else could be included.

8.2. Co-design workshops

Workshop format

Qualitative data were collected via consumer co-design workshops. Consultation took place in the form of face-to-face and online video workshops. Two series of three workshops were run: South Australian participants had the opportunity to participate in face-to-face workshops at the South Australian Health and Medical Research Institute (SAHMRI), and participants in Victoria and New South Wales participated in group workshops via web conference.

Each group of consumer representatives participated in a series of three workshops which followed the structure below.

South Australian and Victorian/New South Wales consumer groups (one in each state):

Workshop 1:

1. Review and provide feedback on PROMs data/information presented using examples of best practice from Australia and other countries, including the AOANJRR patient PROMs dashboards.
2. Generate information on preferred consumer engagement strategies with health information and the impact of COVID-19 restrictions on consumer access to health information.

Workshop 2:

1. Review and provide feedback on key themes identified in Workshop 1.
2. Review and provide feedback on draft design/options developed from workshop 1 to inform design modifications and development of AOANJRR patient PROMs dashboard mock-ups.

Workshop 3

1. Identify and rank PROMs instruments in order of perceived relevance from a consumer representative's point of view.
2. Feedback and comment on final versions of AOANJRR patient PROMs dashboard design samples/templates and best practice principles.

8.3. Consumer representative recruitment

The role of consumer representatives participating in the co-design workshops was to provide a consumer perspective on barriers to accessing health information, what health information is required, and what is best practice for sharing health information with consumers via online channels.

Criteria for participants included having an interest in contributing to health research and a willingness to share their personal experience with either joint replacement surgery or other interactions with the health care sector and accessing health information. Consumer representatives needed to be available to participate in all three workshops, held once every three weeks outside of office hours. Consumers were reimbursed for their preparation and workshop attendance.

The AOANJRR shared the consumer representative expression of interest across a range of organisations and community groups including: Monash Partners (2), The University of Melbourne (3), Safer Care Victoria (4), Musculoskeletal Australia (5), Arthritis SA (6), Health Translation SA (7), Commission on Excellence and Innovation in Health (8), Northern Adelaide Local Health Network (9), Central Adelaide Local Health Network (10), Women's and Children's Health Network (11), the Hamra Centre Library (12), and Health Consumers NSW (13).

The original scope was for the second round of workshops to include Victorian representatives only as prior to COVID-19 these were also planned to be in face-to-face format. However, due to travel restrictions the Victorian workshops were changed to web conference which allowed for some flexibility as to where consumers were located. AOANJRR found that to obtain the required numbers and expand the diversity of the group they needed to expand recruitment to other states in Australia.

8.4. Consumer representative characteristics

A total of 17 consumer representatives participated in the consumer co-design workshops (eight in South Australia, and nine in Victoria/New South Wales) and provided a consumer perspective on accessing health information and patient PROMs dashboards design and use. Across the workshops 47% of participants had direct experience of one or more joint replacements, and 12% had experience of caring for someone who had undergone a joint replacement procedure. In each group, there was one participant with direct experience of a joint replacement who was significantly younger than the average joint replacement patient in Australia who were able to provide a perspective for future of joint replacement data dissemination. Furthermore, 23% of participants had some level of experience of working within the healthcare sector or health research, and 12% had experience caring for someone for a reason other than a joint replacement. Workshop participants were also able to bring a wealth of knowledge and experience from their own careers and life experiences, and 70% had participated in other projects or initiatives as a consumer representative. Participants drew on these varied experiences of interacting with the healthcare sector and health information in workshop discussions.

8.5. Data analysis

The workshops comprised of discussions around how consumer representatives accessed health information, what additional information they felt they needed, and presentations of patient dashboard mock-ups. Consumer representatives were then placed into smaller focus groups with facilitators and examined the dashboard mock-ups in more detail. Breaking up the workshop participants into smaller groups allowed for all voices to be heard and discussions were robust and fruitful. The workshops were recorded and AOANJRR staff took observational notes during the discussions. After each workshop the main themes and subthemes that emerged were identified and summarised by the Project Coordinator and shared with the management group for further analysis and discussion. The main themes and feedback on dashboard mock-ups were then incorporated and presented at the subsequent workshops for further feedback and discussion by consumers.

9. Health information key findings

Consumer representatives were asked a series of questions about how they access health information, what kind of information they would like to have, how their behaviour and attitudes to accessing health information online changed as a result of COVID-19 restrictions, and what kind of information would be most useful to them when accessing patient information dashboards. Both groups came up with very similar responses and key themes are summarised below.

9.1. How consumers access health information

Consumer representatives accessed health information primarily in two ways: from their health practitioner and facility and/or via their own research by conducting internet searches or speaking with their friends, families and their community.

The surgeon or general practitioner was the most commonly cited source of information. Participants also received information from the hospital once they were booked in for surgery. Information was shared both verbally and via pamphlets and booklets. There was a mix of responses about the information which was received: at times information was sufficient, but at other times consumers felt either overwhelmed with the amount of information provided or felt that they were insufficiently informed.

This leads to the other most common response which is that consumers of health information readily sought to conduct their own research via the internet. Consumer representatives utilised Google and YouTube search engines to search for the information they required. They also read blogs written by patients undergoing similar procedures. One consumer representative conducted their own research on specific surgeons and met with a few of them prior to arriving at their decision to have a joint replacement. Consumer representatives also relied heavily on websites that they deemed to be trustworthy, which included Australian Commission on Safety and Quality in Health Care (14), Health Direct (15), Arthritis Australia (16), My Health Record (17), and other websites provided by the Australian Federal Government or State governments. Workshop participants in Victoria mentioned accessing the Better Health Channel (18), Cancer Council Victoria (19), and the COVID-19 daily briefings by Victorian Premier (20) during the series of lockdowns in Victoria throughout 2020/2021.

Consumer representatives cited their networks and communities as a trusted source of information. They drew on experience and knowledge of family, friends and peers from both a patient point of view and from peers who had some level of medical experience or knowledge.

9.2. Gaps in health information

The consensus from consumer representatives across both groups was that they found health information content and accessibility to be both inadequate in its content and scope, and overwhelming in volume (see Appendix 5 for examples).

Accessing information via medical practitioners

Consumer representatives noted that they relied heavily on obtaining information from their medical practitioners. While a range of medical and allied health services were mentioned, the experiences highlighted below were universal:

- They deemed the information from medical practitioners to be biased
- They were not presented with all available treatment options
- There was a belief that private patients received more extensive information than public patients
- Either the information provided was insufficient or participants were presented with a copious amount of paperwork and general information
- Modes of information accessed (e.g. pamphlets, booklets, websites) provided different or contradicting advice

Accessing information independently

When consumer representatives attempted to fill their knowledge gap by conducting their own research, they found it difficult to know where to go and which information to trust; the information

that was available online often conflicted from resource to resource and while some information was correct, consumers felt that much of it was incorrect and misleading. Families and friends were again cited as sources of support for deciphering this information. Participants also noted that the strain of the disease, including feeling overwhelmed, fatigued, emotional or stressed, made it difficult to conduct their own research.

Accessing tailored information

Consumer representatives discussed that they would have found it useful to have information around joint replacements that was tailored at different stages of their joint replacement journey. Workshop participants who had had a joint replacement were seemingly uninformed from the beginning, as most were surprised to learn about the AOANJRR and were frustrated at the lack of communication from their surgeons about the information on prostheses and techniques that the AOANJRR provides. They were also unprepared for what having a joint replacement meant for their ability to participate in their usual activities and ability to work and were not given a clear explanation of the timeline and elements involved with joint replacement preparation to recovery. The difficulties associated with being uninformed were compounded by having to manage allied service providers who did not communicate with each other. This lack of coordination made accessing services difficult and exasperating.

Of note was that consumers who had comorbidities that affected their disease or had a less common disease found it difficult to access adequately nuanced information. They described this as wanting to know about others 'like me'. This lack of guidance was also highlighted by participants who weren't able to access support or information when their disease became acute or unmanageable. Participants felt that health professionals did not attempt to explain the complexities of the disease or how to manage it because of assumptions that lay consumers wouldn't understand it, further adding to feelings of disempowerment.

Implications for diverse populations

Adding on differences in cultural background, language barriers, gender diversity, and other socioeconomic factors made accessing information and facing the issues above that much more challenging. While consumer representatives noted that some services they used provided interpreters or information on their commitment to inclusivity (21), these gestures of support were not enough to help consumers overcome the challenges they faced when accessing the information they needed or making empowered choices about their health.

9.3. Additional health information and support required

Consumer representatives discussed what health information they would have found useful and were forthcoming with suggestions for how information could be composed for lay audiences.

Delivering information to lay audiences

Overall, it was important for consumer representatives to have access to independent and trustworthy information from Australian sources. Consumers made clear that this information should be written and presented with patients in mind, meaning it should be:

- Thorough
- Concise

- Written at Grade 8 reading level; and
- Include no jargon and no acronyms.

Recognising individual patient needs

Participants discussed their need for varying degrees and types of information and support at the different stages of the joint replacement journey. Consumer representatives arrived at the possibility of patient PROMs dashboards filling some of these gaps: the option to discuss PROMs responses with their surgeon would have been a valuable resource for them.

Other important elements of health information discussed included:

- Tailoring information to patients' health concern or surgery
- Providing information on aftercare and home support for carers as well as patients
- Helping patients to set realistic expectations
- Adequately outlining possible complications
- Presenting resources that patients could relate to (e.g. informational videos featuring patients talking to camera)
- Presenting all options for treatment; and
- Providing patient testimonials, including from people with varying outcomes.

Information for joint replacement patients

Workshop participants who had received joint replacements specifically would have liked to have seen more information on ways to prevent joint replacements and an increased willingness on behalf of surgeons to discuss this. Adequate understanding of the range of available prostheses and techniques for arthroplasty was also an important requirement, as was support for setting realistic expectations for surgery results.

At the time participants decided to go ahead with a joint replacement they would have felt more adequately supported if they had had access to a list of what questions to ask their surgeon prior to having their joint replacement, as well information on the range of techniques and prostheses available along with their success rates.

9.4. Impact of COVID-19 restrictions

Given participants already relied on online information, overall there was little change in the way consumer representatives accessed health information since COVID-19 restrictions were implemented. Participants noted that they continued to access health information as they would have before and used the internet for obtaining health information at a similar rate as they had prior to the pandemic.

Accessing telehealth

One noteworthy behaviour shift as a result of COVID-19 restrictions was an increase in use of video and phone consultation with health practitioners.

Consumer representatives found benefits to accessing consultations via telehealth and video call healthcare services. These included that they could benefit some patients who preferred not to or

were unable to leave home due to disability, mobility issues or caring responsibilities, and that it was an efficient way of accessing health services and encouraged health practitioners to keep on time for appointments. For Victorian participants in particular, accessing appointments virtually also helped with feelings of isolation due to both disease but in particular the lockdown and COVID-19 restrictions.

However, face-to-face consultations were still the preferred option. Consumer representatives noted that video and phone consultations came with some disadvantages, including that it could discriminate against patients who did not have access to a strong internet connection or computer hardware. Consumer representatives also noted that the experience overall was not the same as meeting with their health professional in a face-to-face setting, and they didn't feel comfortable to discuss personal issues, preferring instead to use the service to receive results or have a follow-up appointment as opposed to attending the appointment for an initial discussion or diagnosis. Consumer representatives were also concerned about the increased possibilities of data breaches and felt they couldn't trust even the most reliable services when attending video consultations.

Accessing information on COVID-19

Victorian consumer representatives also attempted to access additional health information during the COVID-19 lockdown throughout 2020. These included the Johns Hopkins website on COVID-19 (22), the Coronacast podcast (23), and accessing information via news sites online and via printed newspapers. The participants noted that accessing news on health information had become easier and more useful health information had become available.

10. Health dashboard and PROMs key findings

International examples of best practice from the literature review, and a run through of the current AOANJRR patient PROMs dashboards were presented for discussion at consumer workshops.

10.1. Desirable features of health information dashboards and PROMs reporting

Consumer representatives were asked a series of questions about their attitudes to seeing how their health data compares to others, whether they have used patient dashboards in the past and what their experience of this was, as well as what they would like patient dashboards to look like and include. The responses from the first workshop allowed the AOANJRR to mock up some additional patient dashboard examples to share and discuss at workshops 2 and 3. The result of these co-design sessions were a series of dashboard options as well as an understanding of the key elements patients need and want when accessing their online patient information. A breakdown of suggested dashboard update examples and consumer representative feedback are located in Appendices 1 and 2.

Hierarchy of information

Early in the workshop discussions it became evident that what was believed to be most important from the AOANJRRs point of view was not completely aligned to the viewpoints of consumers.

The AOANJRR currently collects a series of PROMs instruments that cover health status, joint specific scores, comorbidity and expectation questions, as well as additional change and satisfaction questions at the post-operative timepoint. While some of these are relevant from a health service delivery point of view, participants felt that the elements they were most interested in knowing about in relation to their health were:

- What the change has been in their pain and discomfort six months after their joint replacement
- How well they can use their joint
- Their mobility and ability to undertake their usual activities

While overall satisfaction with the joint replacement as a score was placed near the end of the list of importance, participants felt that the indicators outlined above gave an overall picture of the success and therefore satisfaction with the joint replacement.

Key design elements of patient PROMs dashboards

Design elements of patient information dashboards were discussed with workshop participants. Key design points desired include:

- Present specific patient-level information first, then how they patients compare with others like them
- Show what is most important to the patient as opposed to showing all available data upfront
 - o Have option to view more complex/granular data for those who are interested
- Layout should be simple, intuitive, and easy to use
- Key information should be explained through simple infographics and pictures
- Simple graphs help to portray information and progress
- Use of simple and lay language is important, as is avoiding the use of acronyms and jargon
- All pages and key results should be available to download and print
 - o It was also suggested to add a downloadable summary report
- Dashboards need to work across a range of electronic devices (computer, tablet, smartphone, etc.)
- PROMs results should be grouped by theme
- Colours should be bold and help to explain the results (e.g. red indicates worse, green indicates better)
- Layout and colours should take account of people who are visually impaired
- A search option should be available so patients can directly access information they are most interested in

Patient dashboards as tools for accessing information

Consumers noted the potential for patient PROMs dashboards to assist in their ability to take control of their health outcomes as well as assist in their families' understanding of their disease and the recovery process post-surgery. There is an argument here for making patient information dashboards publicly available so they can be accessed by anyone well ahead of the date of surgery. As discussed in Section 9.3., consumer representatives who had had joint replacements would have found it useful to access information well ahead of having a joint replacement. Information highlighted included tips for prevention and preparation, as well as aggregated PROMs data and success rates for various joint replacement techniques and prostheses. This information would have been helpful for both the consumer as well as their family.

Consumers proposed additional information that would have assisted them in their health journey, which included:

- Information on post-surgery care
- Testimonials from other patients or descriptions from the patient point of view of what might be universally helpful to know prior to undergoing a joint replacement
- Questions for patients to ask their surgeon at their initial consultation
- Information on the success rate of prostheses and arthroplasty techniques
- Support in accessing allied health services
- Information for carers
- A resource such as a 'joint replacement journey handbook' that could cover topics such as what is a joint replacement, how to prepare for a joint replacement, how to take care of health after the joint replacement, what happens when it is time to leave hospital, how to make the most out of rehabilitation, and a guided joint replacement care plan
- Additional sources of information and trusted websites, and a description of how these can assist in the patients' joint replacement journey

11. Conclusion

The overarching aim of VAHI-AOANJRR Project was to develop an understanding of consumer interaction with online health information, understand the impacts of COVID-19 on accessing health information in Australia, and to provide recommendations for both improving health information delivery and optimising patient information dashboards.

Key findings of the project included:

- The online health information and patient PROMs data that consumers wanted to see.
- Innovative solutions for presenting patient PROMs data to assist consumers in making informed decisions about their health.
- Key elements of good consumer health information for presentation in online media.
- How much consumers already relied on and gave credence to online information on health issues before COVID19, and how this grew during the pandemic.

Key elements identified were as follows:

- Consumers will seek out trusted sources of information and their surgeon's advice is respected above all other sources of information.
- Health information needs to be tailored to the patient in terms of:
 - o Treatment options
 - o Enough information is balanced with not overwhelming the patient
- Sources of information can be contradictory, so health information needs to be trustworthy and reflect current standards and guidelines.
- Conducting own research as a consumer is difficult, so linking appropriate and trustworthy online sources to websites would help.
- There is a need for a road map to understand likely patient reactions and needs at different stages of surgery and recovery.
- Patient PROMs dashboards should address less common situations or diseases to meet the needs of diverse patients.
- Communicating with diverse populations needs to be considered.
- Online information should be written for a lay audience.
- Visual presentation of information is most effective, so PROMs dashboard format is ideal.

- Patient PROMs dashboards should include information on preventing surgical interventions e.g. joint replacements.

The key findings and elements above provided the basis for clear guidelines for communicating health information online which are outlined below:

Best practice principles for the delivery of consumer-centred health information online

1. Provide consumers with trusted sources of health information

Achieve this by:

- Delivering information through independent, trustworthy, and unbiased websites
- Coordinating health information dissemination with health practitioners, hospitals and private practices
- Developing a communication and engagement strategy that engages a diversity of consumers to increase awareness of available information

2. Write and present health information that is in line with consumer health literacy needs

Achieve this by:

- Producing lay content:
 - Grade 8 reading level (minimal text and simple wording)
 - Lay language and terminology
 - Avoid jargon
 - No acronyms
 - Consider availability of material in a range of languages
- Designing material to assist information uptake:
 - Formatted for a range of digital devices
 - Easy to navigate with clear explanations and instructions
 - Available for print options
 - Adhere to guidelines for visual impairment

3. Provide health information content that will meet the needs of consumers – i.e. is specific to what they are asking for

Achieve this by:

- Co-designing health information resources with consumers
- Presenting only the most relevant information, such as:
 - Specific health concern, surgery and joint
 - Possible complications before they arise
 - Ways to set realistic expectations
- Providing options for consumers to obtain more specific or nuanced information
- Creating a 'my health journey' resource to meet consumer needs at every stage of their health journey

4. Meet consumer needs by sharing PROMs outcome data online

Achieve this by:

- Readily presenting population-level information online to ensure consumers are informed of patient outcomes to assist in shared decision making with their clinician/surgeon

- Provide national results on data that is most relevant to consumers (e.g. satisfaction and improvement) and how their lives will be impacted
 - If possible provide data that is specific to their cohort i.e. gender/age/health status
- b. Providing patient accessible PROMs dashboards to individual patients throughout the journey
 - Information:
 - Only present data that is the most important/relevant to consumers
 - Simple and easy to understand statistics with the option to explore more in-depth data for those interested i.e. tailored to various levels of understanding and need
 - Summary of patient-level data, with ability to share with health practitioner digitally at telehealth appointment or in print at face-to-face consultation
 - Consider:
 - Simple and intuitive navigation
 - Easy to view on a range of devices
 - Use bold colours that are meaningful, simple graphs, and gender-neutral infographics to help explain information
 - Use big and clear font
 - Content should be simple and use the least amount of text as possible
 - Interactive interface

12. References

1. Rolfson O., Eresian Chenok K., Bohm E., Lübbecke A., Denissen G., Dunn J., Lyman S., Franklin P., Dunbar M., Overgaard S., Garellick G., Dawson J. 2016. *Patient-reported outcome measures in arthroplasty registries, Report of the Patient-Reported Outcome Measures Working Group of the International Society of Arthroplasty Registries, Part I. Overview and rationale for patient-reported outcome measures*. Adelaide: Acta Orthopaedica, 3-8.
2. Monash Partners. n.d. Accessed 06 23, 2021. <https://monashpartners.org.au/>.
3. The University of Melbourne. n.d. Accessed 06 23, 2021. <https://www.unimelb.edu.au/>.
4. Victorian Agency for Health Information. n.d. *Safer Care Victoria*. Accessed 06 23, 2021. <https://www.bettersafecare.vic.gov.au/>.
5. Musculoskeletal Australia. n.d. *Musculoskeletal Australia*. Accessed 06 23, 2021. <https://www.msk.org.au/>.
6. Arthritis South Australia. n.d. *Arthritis South Australia*. Accessed 06 23, 2021. <https://arthritissa.org.au/>.
7. Health Translation SA. n.d. *Community Engagement Opportunities*. Accessed 06 23, 2021. <https://healthtranslationsa.org.au/opportunities/community-engagement/>.
8. —. n.d. *Commission on Excellence and Innovation in Health*. Accessed 23 06, 2021. <https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/commission+on+excellence+and+innovation+in+health/commission+on+excellence+and+innovation+in+health>.
9. —. n.d. *Northern Adelaide Local Health Network*. Accessed 06 23, 2021. <https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/our+local+health+networks/northern+adelaide+local+health+network/northern+adelaide+local+health+network>.
10. Government of South Australia. n.d. *Central Adelaide Local Health Network*. Accessed 23 06, 2021. <https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/our+local+health+networks/central+adelaide+local+health+network/central+adelaide+local+health+network>.
11. —. n.d. *Women's and Children's Health Network*. Accessed 06 23, 2021. <https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/our+local+health+networks/womens+and+childrens+health+network/womens+and+childrens+health+network>.
12. City of West Torrens. n.d. *Hamra Centre Library*. Accessed 06 23, 2021. <https://www.westtorrens.sa.gov.au/Hamra-Centre-Library>.
13. Health Consumers NSW. n.d. *Health Consumers NSW*. Accessed 06 23, 2021. <https://www.hcnsw.org.au/>.
14. Australian Commission on Safety and Quality in Health Care. n.d. *For Consumers*. Accessed 06 23, 2021. <https://www.safetyandquality.gov.au/>.
15. Health Direct. n.d. Accessed 06 23, 2021. <https://www.healthdirect.gov.au/>.
16. Arthritis Australia. n.d. Accessed 06 23, 2021. <https://arthritisaustralia.com.au/>.
17. Australian Government. n.d. *My Health Record*. Accessed 06 23, 2021. <https://www.myhealthrecord.gov.au/>.
18. Department of Health, State Government of Victoria. n.d. *Better Health Channel*. Accessed 06 23, 2021. <https://www.betterhealth.vic.gov.au/>.
19. Cancer Council Victoria. n.d. Accessed 06 23, 2021. <https://www.cancervic.org.au/>.
20. Premier of Victoria. n.d. Accessed 06 23, 2020. <https://www.premier.vic.gov.au/>.
21. Quality Innovation Performance. n.d. *Rainbow Tick Standards*. Accessed 06 23, 2021. <https://www.qip.com.au/standards/rainbow-tick-standards/>.

22. Johns Hopkins University of Medicine. n.d. *Coronavirus Resource Centre*. Accessed 06 23, 2021. <https://coronavirus.jhu.edu/map.html>.
23. Swan N., Taylor T. 2020. *Coronacast*. Accessed 06 23, 2021. <https://www.abc.net.au/radio/programs/coronacast/>.

13. Appendices

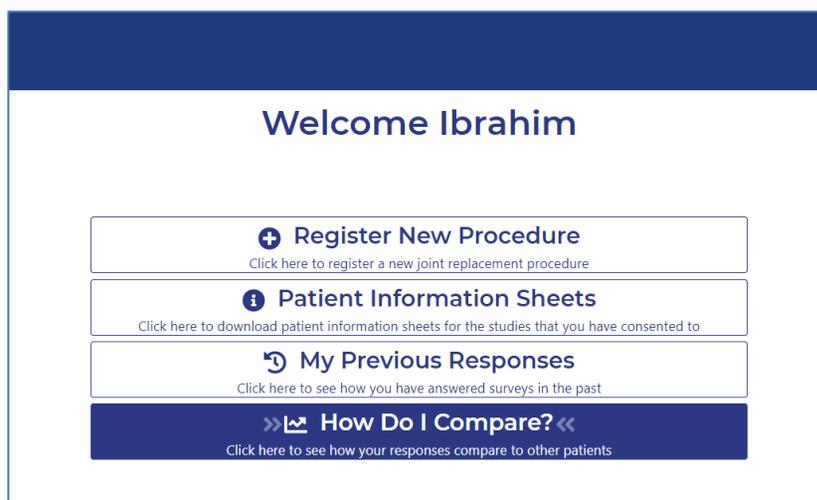
13.1. Appendix 1: PROMs feedback design samples

The images below demonstrate how AOANJRR patient PROMs dashboards are currently presented compared with the co-designed dashboards which were created during the consumer workshops.

Landing page

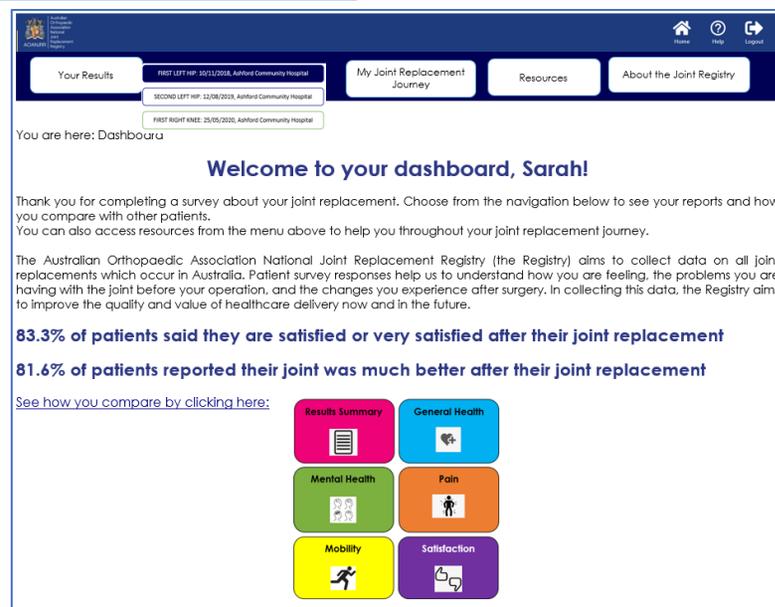
Current AOANJRR Patient PROMs Dashboard

- Data navigation not obvious
- Lack of bright colours (not appealing)



Co-Designed Online Patient Information

- Personalised welcome message
- 'You are here' assisting with navigation



- Some general statistics present an idea of what is available
- 'See how you compare' text provides more information
- Similar categories grouped together/colour coded

Results summary

Current AOANJRR Patient PROMs Dashboard

No option to navigate back to home page

Compare Your Results

Here you can compare the answers you have given with the responses given by other people having the same procedure.

You registered:

Study	Summary
Your Mobility	👁️
Your Personal Care	👁️
Your Usual Activities	👁️
Your Pain and Discomfort	👁️
Your Anxiety and Depression	👁️
Your Health	👁️
Your level of lower-back pain	👁️
Your level of pain in the joint being operated on	👁️
How well you can use your knee and how much pain it causes	👁️
An overall score of pain, function and quality of life as affected by your knee	👁️
A score of the pain you experience going about your usual activities	👁️
A score of the impact of the function of your knee	👁️
A score of the quality of life you experience with your knee	👁️
Your satisfaction with the replacement	👁️
How your joint problem now compares to before you had your operation	👁️

No results available immediately

No instructions about what to do

List of results too long, should be grouped

Co-Designed Online Patient Information

Back to dashboard available button available as well as other navigation options

Descriptive text provided above figure

Sarah - Results Summary

You are here: Dashboard > Results Summary

The figure below shows how your results compare before and after your surgery. The arrows on the right of the line show areas you have improved in and the arrows on the left show the areas that have declined since your surgery. If you would like to know more about what this might mean, we encourage you to speak with your surgeon or general practitioner. You may also find the [resources](#) section of this website helpful.

FIRST LEFT HIP: 10/11/2018, Ashford Community Hospital

Metric	Worse than before surgery	Better than before surgery
Your General Health	0%	80%
Your Pain in the Joint Being Operated	0%	90%
Your Pain and Discomfort	0%	50%
Your Mobility	23%	0%
How Well You Can Use Your Joint	0%	60%
Your Usual Activities	0%	40%
Your Personal Care	0%	33%
Your joint problem now in comparison to pre surgery	39%	0%
Your Satisfaction with the replacement	0%	86%

Relevant results presented immediately

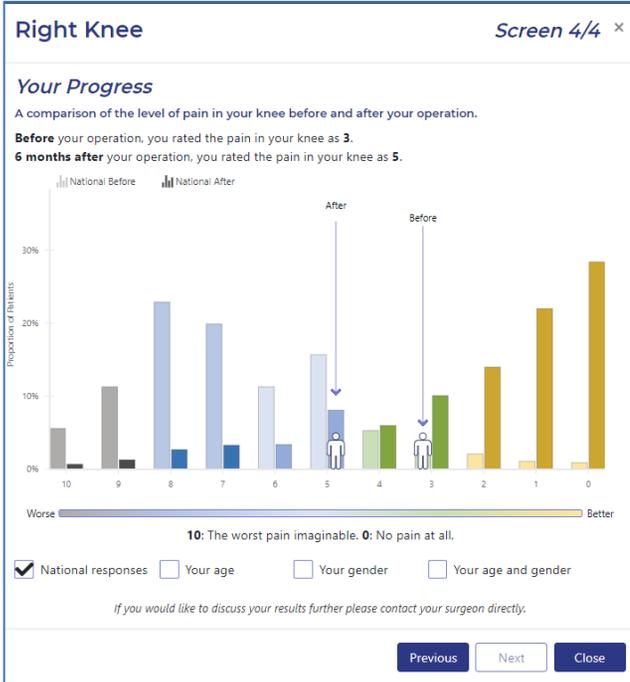
Tiles in navigation bar easy to understand and navigate

Colours used correspond to landing page

Patient results

Current AOANJRR Patient PROMs Dashboard

No explanation for how to interpret graph



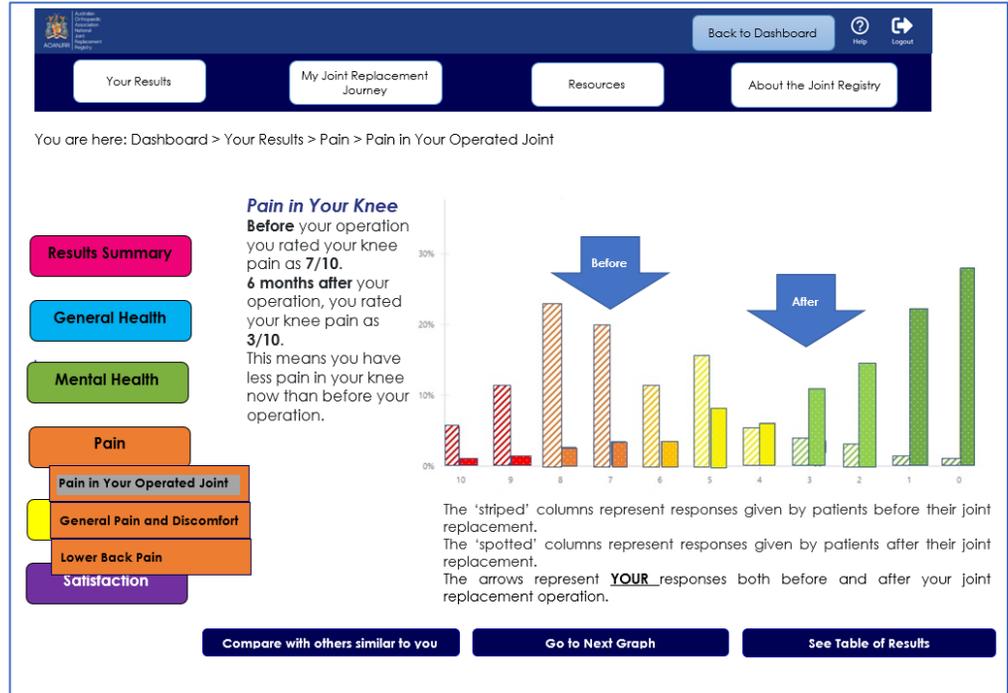
No side panel – no easy way to switch between results

Co-Designed Online Patient Information

Easy to see change before and after

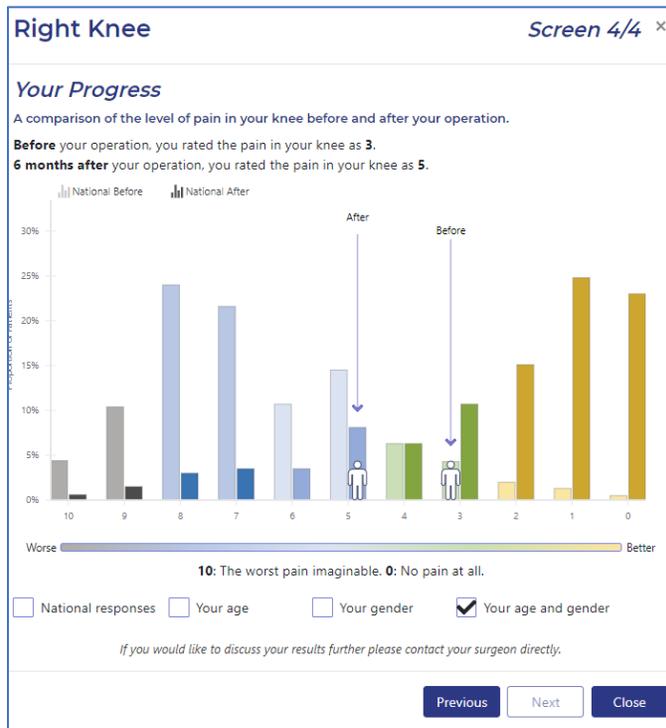
‘You are here’ helps with navigation and explains where consumer is in the website

Text underneath helps to explain graph



Presenting results in different ways

Current AOANJRR Patient PROMs Dashboard



No clear change in screen when 'age and gender' are ticked

Co-Designed Online Patient Information

Which joint the results relate to is visible all the time

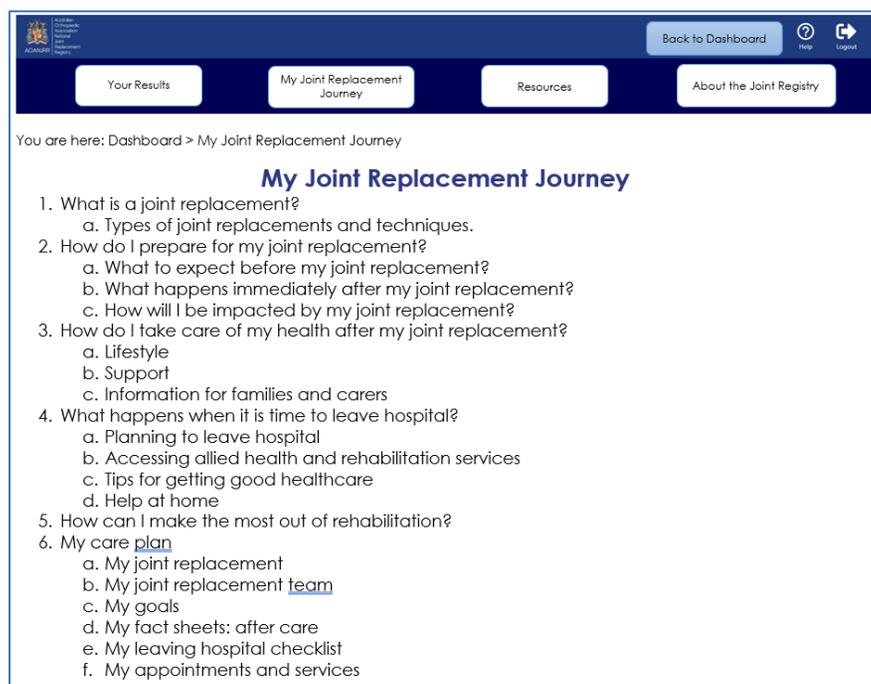
Big arrow shows where patient sits in comparison with national results



When consumers click on the 'compare with others similar to you' the results are explained on the left-hand side

Supporting patients at every stage of the joint replacement journey with a downloadable resource

Co-Designed Online Patient Information



ACALURE
Australasian
Council
on
Arthroplasty

Back to Dashboard Help Logout

Your Results My Joint Replacement Journey Resources About the Joint Registry

You are here: Dashboard > My Joint Replacement Journey

My Joint Replacement Journey

1. What is a joint replacement?
 - a. Types of joint replacements and techniques.
2. How do I prepare for my joint replacement?
 - a. What to expect before my joint replacement?
 - b. What happens immediately after my joint replacement?
 - c. How will I be impacted by my joint replacement?
3. How do I take care of my health after my joint replacement?
 - a. Lifestyle
 - b. Support
 - c. Information for families and carers
4. What happens when it is time to leave hospital?
 - a. Planning to leave hospital
 - b. Accessing allied health and rehabilitation services
 - c. Tips for getting good healthcare
 - d. Help at home
5. How can I make the most out of rehabilitation?
6. My care [plan](#)
 - a. My joint replacement
 - b. My joint replacement [team](#)
 - c. My goals
 - d. My fact sheets: after care
 - e. My leaving hospital checklist
 - f. My appointments and services

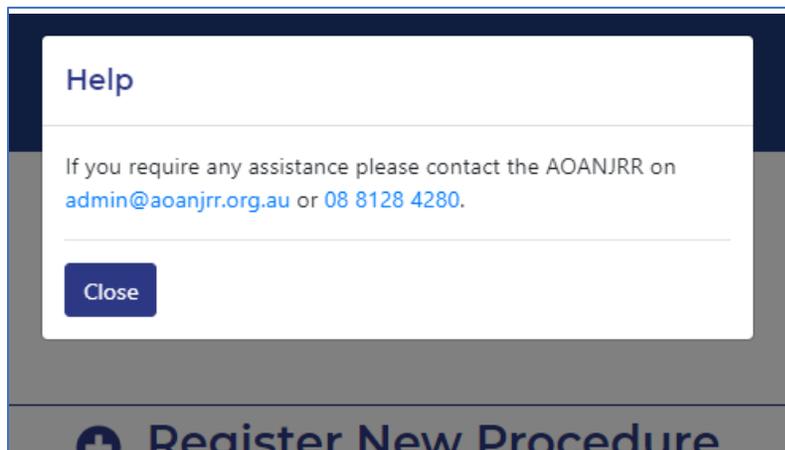
'My Joint Replacement Journey' would be a printable resource

Consumer representatives said this would be a helpful resource to guide them through their health journey

This resource assists consumers with every stage of their joint replacement journey and assists them in navigating their appointments and allied health services

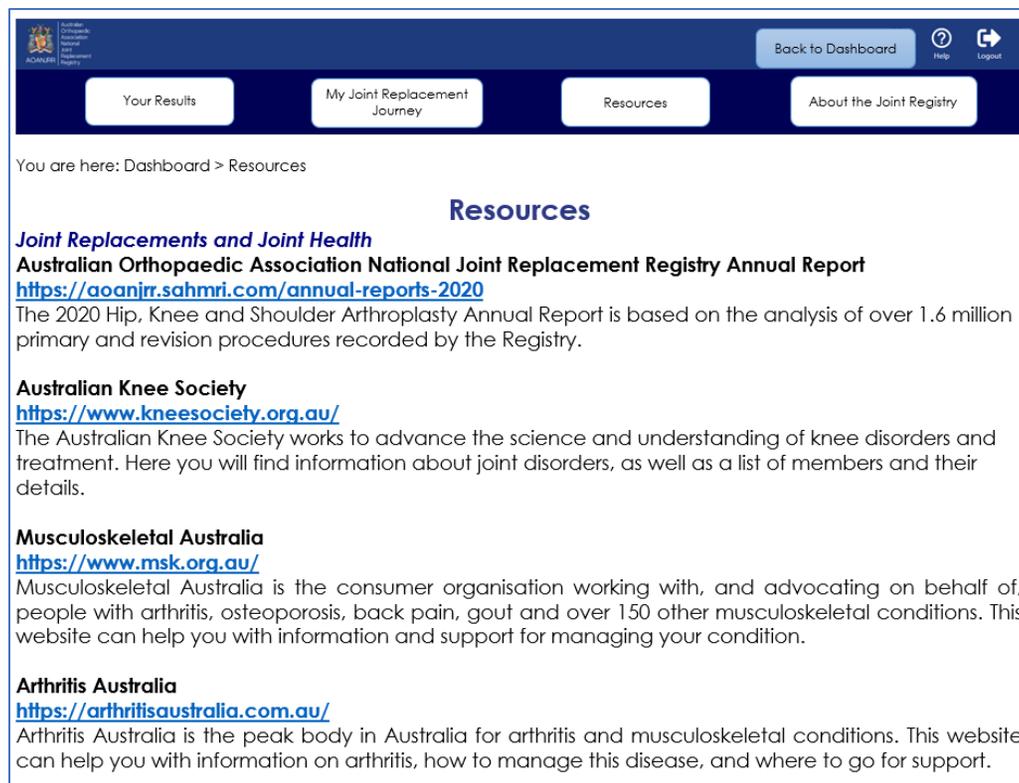
Additional resources

Current AOANJRR Patient PROMs Dashboard



Currently no additional resources available. Only option is to contact the AOANJRR for assistance

Co-Designed Online Patient Information



The 'Resources' page could help alleviate some problems consumers have with not knowing which organisations to trust and where to go to access the information they need

13.2. Appendix 2: Updated dashboards in response to consumer representative comments

Consumer representatives were given the opportunity to review and comment on examples of PROMs reporting at the first of three workshops. Consumer representative workshops were then structured to iteratively approach the design of patient PROMs dashboards and were guided by the specific comments and feedback itemised below.

Categories of Desirable Features	Consumer Representative Comments and Corresponding Health Information Elements																														
<p>Most important information to present</p>	<div data-bbox="976 467 1596 950" data-label="Figure"> <p>Results Summary</p> <p>The figure below shows how your results compare before and after your surgery. The arrows on the right of the line show areas you have improved in and the arrows on the left show the areas that have declined since your surgery. If you would like to know more about what this might mean, we encourage you to speak with your surgeon or general practitioner. You may also find the resources section of this website helpful.</p> <p>FIRST LEFT HIP: 10/11/2019, Ashford Community Hospital</p> <table border="1"> <thead> <tr> <th>Metric</th> <th>Before Surgery</th> <th>After Surgery</th> </tr> </thead> <tbody> <tr> <td>Your General Health</td> <td>25%</td> <td>80%</td> </tr> <tr> <td>Your Pain in the Joint Being Operated</td> <td>25%</td> <td>90%</td> </tr> <tr> <td>Your Pain and Discomfort</td> <td>25%</td> <td>50%</td> </tr> <tr> <td>Your Mobility</td> <td>51%</td> <td>23%</td> </tr> <tr> <td>How Well You Can Use Your Joint</td> <td>51%</td> <td>60%</td> </tr> <tr> <td>Your Usual Activities</td> <td>51%</td> <td>40%</td> </tr> <tr> <td>Your Personal Care</td> <td>51%</td> <td>32%</td> </tr> <tr> <td>Your joint problems prior to surgery</td> <td>51%</td> <td>39%</td> </tr> <tr> <td>Your Satisfaction with the replacement</td> <td>51%</td> <td>90%</td> </tr> </tbody> </table> </div> <ul style="list-style-type: none"> - Prefer to not be overwhelmed with information, and just have access to what is most relevant - Good to have key points around patient's personal progress - Make important information stand out - Like the simple summary of results and to easily see how patient has improved or regressed - Ranking exercise of PROMs instruments demonstrated that consumer representatives are most interested in their own progress, their pain and discomfort, their mobility and how well they can use their joint, and their ability to participate in their usual activities. Measures such as general health, mental health, and lower back pain were less of a priority. 	Metric	Before Surgery	After Surgery	Your General Health	25%	80%	Your Pain in the Joint Being Operated	25%	90%	Your Pain and Discomfort	25%	50%	Your Mobility	51%	23%	How Well You Can Use Your Joint	51%	60%	Your Usual Activities	51%	40%	Your Personal Care	51%	32%	Your joint problems prior to surgery	51%	39%	Your Satisfaction with the replacement	51%	90%
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Your Personal Care	51%	32%																													
Your joint problems prior to surgery	51%	39%																													
Your Satisfaction with the replacement	51%	90%																													

<p>Presenting data in an accessible way</p>	<div data-bbox="905 188 1661 415" style="border: 1px solid black; padding: 5px;"> <p>See how you compare by clicking here:</p>  </div> <ul style="list-style-type: none"> - Lay wording, no acronyms - Need to take account of people with low computer literacy - Simplify the wording (don't need to have complete sentences) - Visuals should support people from CALD communities - Icons need to be relevant and obvious if they are used - Group similar topics together e.g. pain - Prefer a neater dashboard
<p>Support for navigating dashboard</p>	<div data-bbox="911 646 1661 776" style="border: 1px solid black; padding: 5px;">  </div> <ul style="list-style-type: none"> - Need instructions/information on how the dashboard works - Need to always be able to easily navigate back to resources and homepage - Need to clearly show procedure details - Button should include hospital and date of surgery to assist in distinguishing between multiple procedures <div data-bbox="1121 948 1352 1365" style="border: 1px solid black; padding: 5px;">  <p style="font-size: small; margin-top: 5px;">Pain Before you rd pain d 6 mor operd your k 3/10. This m less pi now t operc</p> </div>

	<ul style="list-style-type: none"> - Like consistency of colour use - Would be good to have the opportunity to 'hover over' some elements and have information that helps patients to navigate the dashboards - Do not options which are not linked to results or information <div data-bbox="905 321 1572 391" style="border: 1px solid black; padding: 5px; margin: 10px auto; width: fit-content;"> Compare with others similar to you Go to Next Graph See Table of Results </div> <ul style="list-style-type: none"> - Each button to move to next graph should be more specific e.g. post-op, your change, compare with others similar to you, etc.
Additional information needed	<div data-bbox="856 464 1715 732" style="border: 1px solid black; padding: 10px; margin-bottom: 10px;"> <p style="text-align: center;">Welcome to your dashboard, Sarah!</p> <p>Thank you for completing a survey about your joint replacement. Choose from the navigation below to see your reports and how you compare with other patients. You can also access resources from the menu above to help you throughout your joint replacement journey.</p> <p>The Australian Orthopaedic Association National Joint Replacement Registry (the Registry) aims to collect data on all joint replacements which occur in Australia. Patient survey responses help us to understand how you are feeling, the problems you are having with the joint before your operation, and the changes you experience after surgery. In collecting this data, the Registry aims to improve the quality and value of healthcare delivery now and in the future.</p> <p>83.3% of patients said they are satisfied or very satisfied after their joint replacement</p> <p>81.6% of patients reported their joint was much better after their joint replacement</p> </div> <ul style="list-style-type: none"> - Needs to be more personal e.g. 'welcome to your dashboard' - Need to have description on main page giving more information about the project - Need a header page about the organisation, how it respects privacy, and the purpose for collecting data - Useful to have some information on homepage so people have an idea of what they can review - Would like to see an overall picture of national results <div data-bbox="856 899 1617 1344" style="border: 1px solid black; padding: 10px; margin-bottom: 10px;"> <p style="text-align: center;">Resources</p> <p>Joint Replacements and Joint Health Australian Orthopaedic Association National Joint Replacement Registry Annual Report https://aoanjrr.sahmri.com/annual-reports-2020 The 2020 Hip, Knee and Shoulder Arthroplasty Annual Report is based on the analysis of over 1.6 million primary and revision procedures recorded by the Registry.</p> <p>Australian Knee Society https://www.kneesociety.org.au/ The Australian Knee Society works to advance the science and understanding of knee disorders and treatment. Here you will find information about joint disorders, as well as a list of members and their details.</p> <p>Musculoskeletal Australia https://www.msk.org.au/ Musculoskeletal Australia is the consumer organisation working with, and advocating on behalf of, people with arthritis, osteoporosis, back pain, gout and over 150 other musculoskeletal conditions. This website can help you with information and support for managing your condition.</p> <p>Arthritis Australia https://arthritisaustralia.com.au/ Arthritis Australia is the peak body in Australia for arthritis and musculoskeletal conditions. This website can help you with information on arthritis, how to manage this disease, and where to go for support.</p> </div> <ul style="list-style-type: none"> - If results are poorer than expected, who can patients contact?

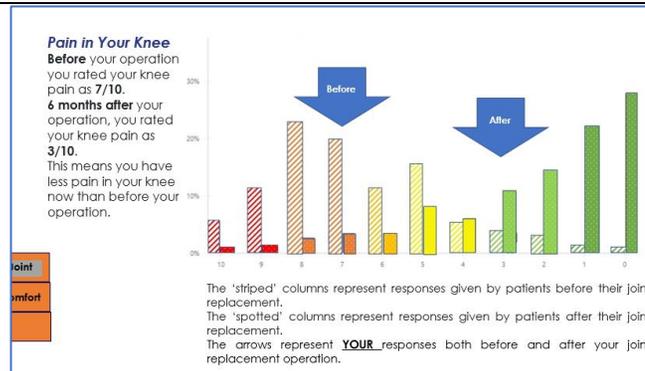
- Find it difficult to know where to go and which information to trust
- Need information on available medical treatments post-surgery
- Different types of resources are good to have

My Joint Replacement Journey

1. What is a joint replacement?
 - a. Types of joint replacements and techniques.
2. How do I prepare for my joint replacement?
 - a. What to expect before my joint replacement?
 - b. What happens immediately after my joint replacement?
 - c. How will I be impacted by my joint replacement?
3. How do I take care of my health after my joint replacement?
 - a. Lifestyle
 - b. Support
 - c. Information for families and carers
4. What happens when it is time to leave hospital?
 - a. Planning to leave hospital
 - b. Accessing allied health and rehabilitation services
 - c. Tips for getting good healthcare
 - d. Help at home
5. How can I make the most out of rehabilitation?
6. My care [plan](#)
 - a. My joint replacement
 - b. My joint replacement [team](#)
 - c. My goals
 - d. My fact sheets: after care
 - e. My leaving hospital checklist
 - f. My appointments and services

- Difficult to navigate the health system and providers don't talk to each other
- Not given clear explanation of timeline and elements that assist with recovery
 - o Need access to different levels of information at different stages of disease and recovery
 - o Need a treatment plan: what happens, when does it happen and who delivers the service
 - o Need a realistic timeline of joint replacement journey and treatment plan
 - E.g. when can expect to take time off
 - How long recovery can take
 - What rehabilitation stages look like and what to expect

Design and layout requirements



- Needs to be user friendly across devices
- Writing needs to be big and easy to read
- Need to incentivise patients to visit their dashboard e.g. show them how they have improved
- Don't cram too much information on one page
- No acronyms
- Want the ability to download and print the information
- Prefer bold colours as opposed to light
- Need to take account of people who are colour-blind
- Include the ability to increase size of text
- Like colours of graphs to have meaning – red for bad and green for good
- Need to see easily see where I sit in comparison to national results

13.3. Appendix 3: Literature review



AOANJRR

Australian
Orthopaedic
Association
National
Joint
Replacement
Registry

VAHI – AOANJRR Project: Examining International Excellence in PROMs Implementation

Prepared by AOANJRR

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Executive Summary

This research builds on the back of the AOANJRR's pilot PROMs trial, completed in early 2020. The trial saw the construction and testing of a PROMs system to capture patient reported outcomes for joint replacement surgery. To further develop the PROMs system, this study hopes to provide greater knowledge on the optimal design of online PROMs, particularly focussing on developing engaging patient feedback reporting.

By examining the fundamental strengths of the world's top PROMs systems, this study aims to identify possible means of improvement for the AOANJRR. A literature review on PROMs theory provides the theoretical background required to examine international exemplars. Case studies from the USA to Sweden were found, covering national, hospital and registry uses of PROMs. These cases are the focus of this investigation as its central aim is to identify and learn from international excellence in PROMs. From the analysis of these cases, a set of criteria has been developed that describes the common traits of the most successful PROMs programs.

Critical to modern PROMs systems is the creation of a functional online platform to allow patients to complete and review their PROMs. Consequently, following the examination of case studies, a review of the literature on data and online PROMs engagement principles has been undertaken.

The derived criterion for PROMs excellence and online data engagement can then be used to analyse the strengths and weaknesses of the PROMs system developed by the AOANJRR. Specifically, the systems for patient completion of PROMs, patient feedback reports and clinician feedback reports have been studied. In brief, the resulting recommendations provided to the AOANJRR are as follows:

- A) Increase clinician training on the functions of PROMs data to increase usage and value in consultations.
- B) Review patient follow up timelines and post operation communication methods.
- C) Redesign the patient feedback reporting dashboard to better engage patients.
- D) Liaise with clinicians to build a system that allows online communication between clinician and patient regarding PROMs data.
- E) Generate supplementary information for the PROMs program on uses of the data for patients and clinicians.
- F) Design a tool for hospitals and providers to understand role of PROMs and aid practical implementation in their systems.

Background and Rationale

The Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR) functions to improve and monitor the quality of care for individuals undergoing joint replacement surgery. Patient Reported Outcome Measures (PROMs) are simple surveys designed to collect information on patient outcomes. They are being adopted globally to drive patient centred care, integrating the patient's perspective formally into the health system. Outcomes data can be analysed and fed back to clinicians, health providers or patients to identify patient needs and guide more effective interventions.

All hospitals in Australia that perform joint replacement surgery provide data to the AOANJRR. In light of growing demands for patient centred care, the registry decided that there may be value for surgeons and patients in also collecting patient reported outcomes data. Consequently, they embarked on a pilot project in 2018 to build and test a specifically designed online PROMs system for implementation across Australia. The trial involved hospitals from across the country and provided valuable lessons on the positive benefits of PROMs, as well as the challenges remaining for successful implementation (1).

The optimal design of patient feedback reports remains an ongoing area of research for the AOANJRR and the medical community more broadly. Consequently, this study aims to provide potential solutions by synthesizing best practice knowledge on the characteristics of leading PROMs programs.

To support the effective analysis of these global exemplars, a solid understanding of the theoretical basis of PROMs is required. Furthermore, the AOANJRR has built an online system and thus to design the optimal PROMs feedback mechanisms, research must also be conducted into the principles of designing captivating online health infrastructure. This report begins by covering the basic theory of PROMs in healthcare, before examining case studies and data engagement principles. The summation of knowledge gathered in these sections is then used to analyse and produce recommendations for the AOANJRR PROMs system.

Methodology

Research has been conducted through online literature search covering academic and grey literature sources. Database searches have been performed in SCOPUS and PubMed. Keywords and phrases such as 'Patient empowerment' and 'PROMs feedback reporting', have been used as well as many other variations using 'PROMs', 'Engagement' and 'Feedback'. It should also be noted that resources and case studies from the International Consortium for Health Outcomes Measurement (ICHOM) have been used regularly. Research is limited only to literature search at this time, with expert interviews not conducted.

PROMs Background Literature Review

PROMs are used to assess and describe a patient's own feelings and perceived function. They originated in clinical trials to assess the efficacy of treatments (2). Over the past two decades PROMs have grown across the globe, and it is important to note that PROMs have been extensively reviewed previously and this short literature review will only cover essential explanatory information.

The theory of change for PROMs perceives feedback as the first key step in garnering formal support for patient choice (3). Using this information, patients can work with clinicians or by themselves to assess the appropriate provider and surgery. It is theorised this feedback to the clinician will then improve patient care by placing ownership on the clinician to protect their

personal reputation and satisfy their desire for improvement by achieving the outcomes the patient wants (3).

Another way to interpret PROMs benefit to patients is by direct or indirect mechanisms. Indirect benefits occur when PROMs are used by providers to guide improvement by measuring success. Greenhalgh proposes that this can benefit patients by driving competition for the highest quality care between different hospitals (3). Indirect benefits may also occur when PROMs are used to improve surgical practice. Outcomes data from particular surgeon's patients may provide insight on areas to improve, thus benefitting the next patient. This outcomes data is unique as no other system provides quantitative indications to clinicians on the specific areas that patients are satisfied or not with (3).

Softer theories for PROMs impact also exist, with research suggesting a more precise discussion of symptoms facilitated by PROMs simply allows clinicians to determine a more appropriate course of treatment (4). PROMs can also generate direct benefit by enabling self-management, goal setting and improving ties to the healthcare system. Self-management may be particularly important for those with chronic conditions and PROMs offer a method to monitor their progress and keep them interacting with the health system (5). This is an emerging area of use for PROMs that is noted by many authors as requiring further research (6)(7). Simply using PROMs to improve pre-op engagement has been shown to correlate with greater pain relief post-op (8).

For PROMs to succeed, clinicians must engage and be willing to discuss the outcomes information with the patient (4). Clinicians may be opposed to PROMs as it can alter their traditional role and introduce potential burdens on their clinical practice (4). As a result, if PROMs are to achieve their desired outcome, clinicians must be shown the value of PROMs before they are mandated. For example, Greenhalgh suggests that PROMs may not shift the focus of a consultation onto psychosocial issues as clinicians simply do not perceive this as part of their role (3). Biomedically focussed clinicians who have not been trained may also be confronted by problems raised by PROMs that they are simply not equipped to handle (3).

A PROMs program can be implemented by registries, hospitals or clinics, or across a system of providers such as the NHS. Design varies greatly and the guiding principles are outlined in this report during the examination of international PROMs exemplars. Each institution must decide on general or condition specific PROMs, the mode of delivery and their ideal methods for feedback. General PROMs gather information on general quality of life, whilst conditions specific PROMs such as the Oxford Knee Score provide information related to the surgery in question (1). PROMs can be delivered through paper or online systems. Paper systems are easier for patients to understand and complete, but online systems are more efficient and reduce burden. Feedback reports may also be online or paper, with online systems offering greater flexibility and customisation (2). Designing a PROMs program requires careful planning and to be effective must consider many factors. Figure 1 has been produced by researchers and eloquently captures the diverse areas that must be considered when implementing PROMs in clinical registries such as the AOANJRR.

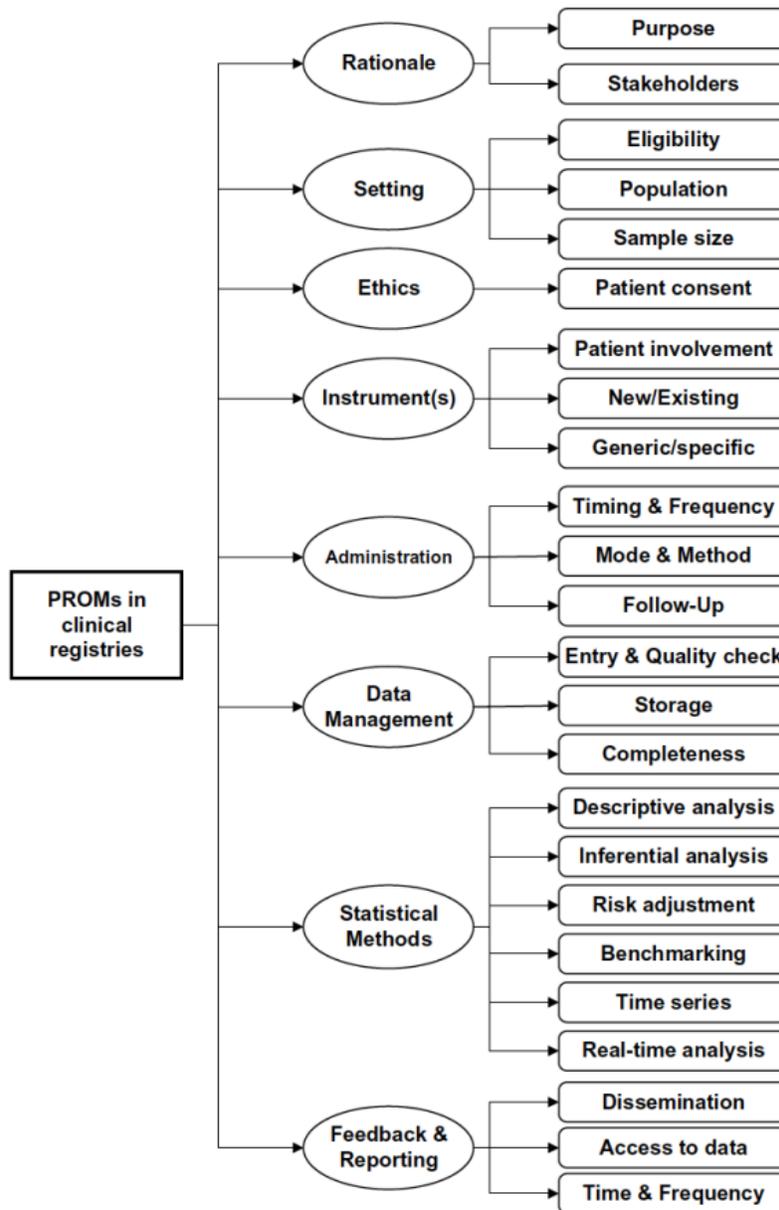


Figure 1: Conceptual framework for a clinical registry planning to implement a PROMs program (9)

Many barriers exist to PROMs implementation, from under resourcing to a simple need for more research on the best methods available. The perceived increase in workload from PROMs can prevent their use, whilst patients may have concerns about confidentiality and the true usefulness of this data (4). Alongside logistical challenges is the cultural shift required by clinicians and patients to successfully adopt PROMs. In many situations, PROMs signify a shift away from patriarchal forms of care to a more collaborative two-way relationship and this requires education and adaptation by all stakeholders.

International Exemplars of PROMs Engagement

PROMs have been implemented widely, yet there remains little global consensus on best practice or design. Many models have been trialled at different levels of the health system, with registries specifically trialling many options. Given the lack of consensus and the array of possible designs available, an analysis of specific case studies will aim to distil more specific characteristics that underly successful PROMs programs.

Cases have been chosen for registries, national health systems and private institutions. The analysis of the national and registry systems provide insight on optimal design principles for large scale PROMs systems. In contrast, leading techniques for patient feedback and engagement are best represented through analysis of smaller patient facing programs such as hospital or clinic-based exemplars.

Case Study 1: NHS National PROMs system

PROMs have been in place across the United Kingdom's National Health Service (NHS) since 2009 and this represents one of the first system wide adoptions of PROMs. The Department of Health began the program by mandating the reporting of patient outcomes before and after hernia, varicose vein and knee and hip replacement surgeries. Over the years, the program has expanded greatly to include many other surgeries and optimise data collection practices. It is now administered exclusively by the NHS and data is reported through NHS Digital. To join the program, hospitals or other providers must become accredited and demonstrate an ability to comply with the demands of the program (10).

Data Collection

Although the NHS gathers PROMs on a range of operations, only the data collection for knee and hip replacements will be examined. Patients must first give consent to the use of PROMs and the logging of their data at registered providers. General and condition specific measures are used. Relevant measures used for knee and hip replacement includes (11):

- 3 level version of EQ-5D
- EQ VAS
- Oxford Hip Score
- Oxford Knee Score

For knee and hip replacements PROMs are administered no more than 18 weeks before the operation and 6 months after (11). They are designed to require no assistance, but exemptions can be made for patients to enlist friends or family to overcome technological and language barriers. Whether the questionnaires are delivered online or by paper remains at the discretion of the provider, but it is advised that the most appropriate medium for the specific patient population is chosen (11). It is then the responsibility of the provider to deliver the PROMs, whether that be by email for online PROMs or paper PROMs in clinic.

For online PROMs, the NHS has produced specific design guidelines to ensure comparability no matter the provider. Interestingly, they have also asserted that they must replicate paper options as much as possible. This has been instituted in order to ensure those that offer paper PROMs are not disadvantaged. However, it is interesting to note that research has suggested engaging online PROMs delivery increases completion (9). For example, the NHS currently mandates that

all online PROMs must have a 7:1 contrast ratio and use sans serif or another NHS approved font (11).

PROMs Feedback

The programme's focus on system wide quality improvement is not conducive to highly personalised PROMs feedback. The NHS generates patient benefit from PROMs through more informed decision making on which hospital to choose and a greater understanding of the average outcomes of their nominated procedure.

To do so, the NHS provides comparative data on the quality of health care providers and reports on the success of specific surgeries such as knee replacements. This includes data on:

- Health Gain
- Complication Rates
- Satisfaction
- Improvement rate
- Condition Specific Measures

The system wide reporting on complication rates and satisfaction also prepares and educates patients on the possible outcomes of their surgery (12). In principle, it is hoped that patients will then be able to better self-manage their condition, particularly if data is used in consultation with clinicians.

The data is delivered through regular reports published online by NHS Digital. Outcomes statistics are released each month, alongside annual reports and quarterly special topic reports. The data is presented by dedicated statisticians and in a formal manner. It is clear the data is predominantly designed for health providers so they may address their performance. Data is presented in bar charts and tables, with access to raw data also available.

Other resources on PROMs are available on NHS digital. One example which is potentially more accessible for patients is an online interactive presentation of the yearly report (12). Users can customise which region, measure or specific provider they would like to view information for. There is also an option to view a range of outcomes such as walking difficulty and the average improvement for these outcomes that patients are currently achieving. This resource enables patients to better utilise the outcomes measures to judge their expectations for surgery and choose a location for treatment (12).

Key Strengths

- Pioneering health system level PROMs programme that has demonstrated the benefits of outcomes data to prospective patients and efficiency minded healthcare providers.
- High powered data sets that are accessible to the public, allowing individuals to be better informed when selecting their appropriate and optimal location of treatment.
- Collates PROMs from many providers across a range of surgeries. The volume of PROMs data is unmatched globally and is used as an indicator of overall health system performance year to year.
- Supported by government and used in NHS policy to identify the needs of the patient and general community.
- Initial program has paved the way for a range of other policies such as the NHS Outcomes Framework which further the adoption of value based health care strategies.

Key Weaknesses

- Minimal focus on individual patient feedback of data.
- Data is designed for providers via large data packets and official monthly statistics that discourage active use by patients. This combined with a high complexity of data results in poor transparency and direct communication to patients.
- Large top down system creates generic PROMs delivery, not necessarily catering for creative design or targeted engagement of specific populations.
- Hospitals can be averse to their use as the scores are skewed by the nature of the patient population and the hospital. May deter consumers.

Case Study 2: Swedish Hip Arthroplasty Registry

Currently Sweden possess approximately 90 different national quality registers covering many conditions. The registries have collected PROs for nearly two decades using both disease specific and generic PROMs. Registries are obliged to incorporate PROs in practice to achieve certification, with one in five reportedly using the data directly for local quality improvement (13). The Swedish Hip Arthroplasty Registry is a leading user of PROMs in Sweden, collecting data to drive quality and create shared decision-making tools for clinicians. The registry logs surgical and semi-prosthetic operations, covering up to 98% of whole hip prostheses procedures in Sweden (14). The registry has used its data for research purposes, presented it to the public to guide decision making and educated clinicians on using PROMs during consultations.

Data Collection

The initial PROMs are delivered via an internet-based system. However, they are designed to only be completed in clinic before the operation. This enables immediate access to results and eliminates any issues with legibility or incorrect registration. Currently, follow up questionnaires are not online though, instead mailed to patients at one, six and ten year intervals (14). In clinic PROMs can increase burden on the clinic, whilst mailed paper follow ups increase the risk of non-completion compared to online systems.

Given the registry is not directly interacting with patients, they liaise heavily with clinics to distribute lists of those requiring follow up. Providers are required to register patients and ensure that all information provided is up to date and entered into the registry database.

Nevertheless, these practices may be considered a success as they have reported strong completion rates amongst patients and a growing use of PROMs by clinicians in pre-operative decision making (14).

The PROMs used are relatively simple and are as follows:

- EQ-5D Index
- EQ VAS
- Charnley Categories

The registry provides extensive detail on its website for clinicians and patients about privacy, the construction of the surveys and data entry processes (<https://shpr.registercentrum.se/>). Support for healthcare professionals is particularly significant, with the registry providing clear tutorials on

how clinicians can register and advice on explaining the use of PROMs to patients. As noted by Greenhalgh, for PROMs to have their maximum impact, it requires clinician buy in and an understanding of the benefits of PROMs in decision making (3).

Feedback

The PROs data can be accessed through many mediums, varying in their complexity and target audience. The registry's annual report uses PROMs as an indicator of the country's successes and the potential challenges remaining.

It is also noted that PROMs data can be provided on request to different stakeholders, whether that be specific providers, other registries or implant manufacturers (14).

The current system has minimal focus on providing personalised information to patients, prioritising national level data and clinician improvement. Currently, patients can only access individualised information contained in the registry by formal request. Nevertheless, the registry has acknowledged one of its future aims as providing more personalised information for patients. They hope that this will allow clinicians to better inform and predict the expected benefits and risks of an operation for individual patients.

For patients, the best way to currently access population outcomes data is through the registry's website. There is a section dedicated to patients which provides data and accompanying explanatory information. Specifically, the website presents clear graphs on:

- Reoperation rates
- Pain rating
- Satisfaction
- General Health

A 'Check the situation' tool is also available to the public through which they can compare providers in a range of categories including (15):

- Satisfaction
- 1, 6- and 10-year implant survival
- Reoperation
- Case mix
- Side effects after 90 days

This tool is interactive, allowing patients to apply advanced filters on sex, age, BMI and many other indicators. Once again, the registry critically provides a detailed explanation of the indicators and concepts required to effectively interpret the data.

Strengths

- Range of resources and support tools for clinicians to allow easier uptake of PROMs into standard clinical practice.
- Availability of data and accompanying information online for patients. Interactive elements and the ability for individuals to filter for specific data is also important to increasing transparency and usefulness of the data.
- Historic partnership with rigorous research that has seen PROMs data used to advance techniques across Sweden.

- Supported well by government and the national quality register system that normalises the collection of outcomes data and demonstrates best practice systems.

Weaknesses

- Minimal focus on self-management of patients, focussing on providing data to clinicians and providers.
- Registration and completion only occur in clinic, thus increasing its burden on clinics and limiting the programs accessibility for geographically isolated patients.

Case Study 3: Erasmus University Medical Centre Cleft Lip and Palate PROMs

The Erasmus University Medical Centre is one of the largest academic medical centres in Europe. Since 2013, the centre has explored programs to promote value-based health care, researching the metrics and systems required to define success in the institution.

A specific pilot project was designed for Erasmus MCs Cleft department, one of the largest in the Netherlands. A global standard set of outcomes for Cleft Lip and Palate (CLP) was developed in 2015 by ICHOM and was used by Erasmus MC as the basis for the program.

CLP begins in children, requiring long-term management, multiple interventions and a range of specialists. Consequently, improvement in management presents an important opportunity to increase value of treatments and reduce the burden on patients and the health system. The program uses clinician and patient reported outcomes regularly to track progress and guide treatment of CLP across long time periods (16).

Development Process

To design a program for a multi-disciplinary disease such as CLP, Erasmus MC began by assembling a team of specialists in computer science, business intelligence and clinical CLP management. Having developed a project management team, the next steps were to develop the software for data collection, begin patient consultation and undertake a review of current patient care pathways to identify optimal data collection points. The patient consultation period sought feedback on design preferences and educated patients to ensure improved uptake of an outcomes driven management approach. This occurred through patient focus groups, detailed brochures and the emailing of information on web-based PROMs tools, changes to clinical flow and altered treatment schedules (16).

Data Collection

The program used online PROMs tools to collect responses and provide outcomes data to the clinician. Online collection was favoured to reduce burden in clinic and done through automated email reminders. Exceptions could be made to collect data in clinic, with the desired collection process shown below in Figure 2.

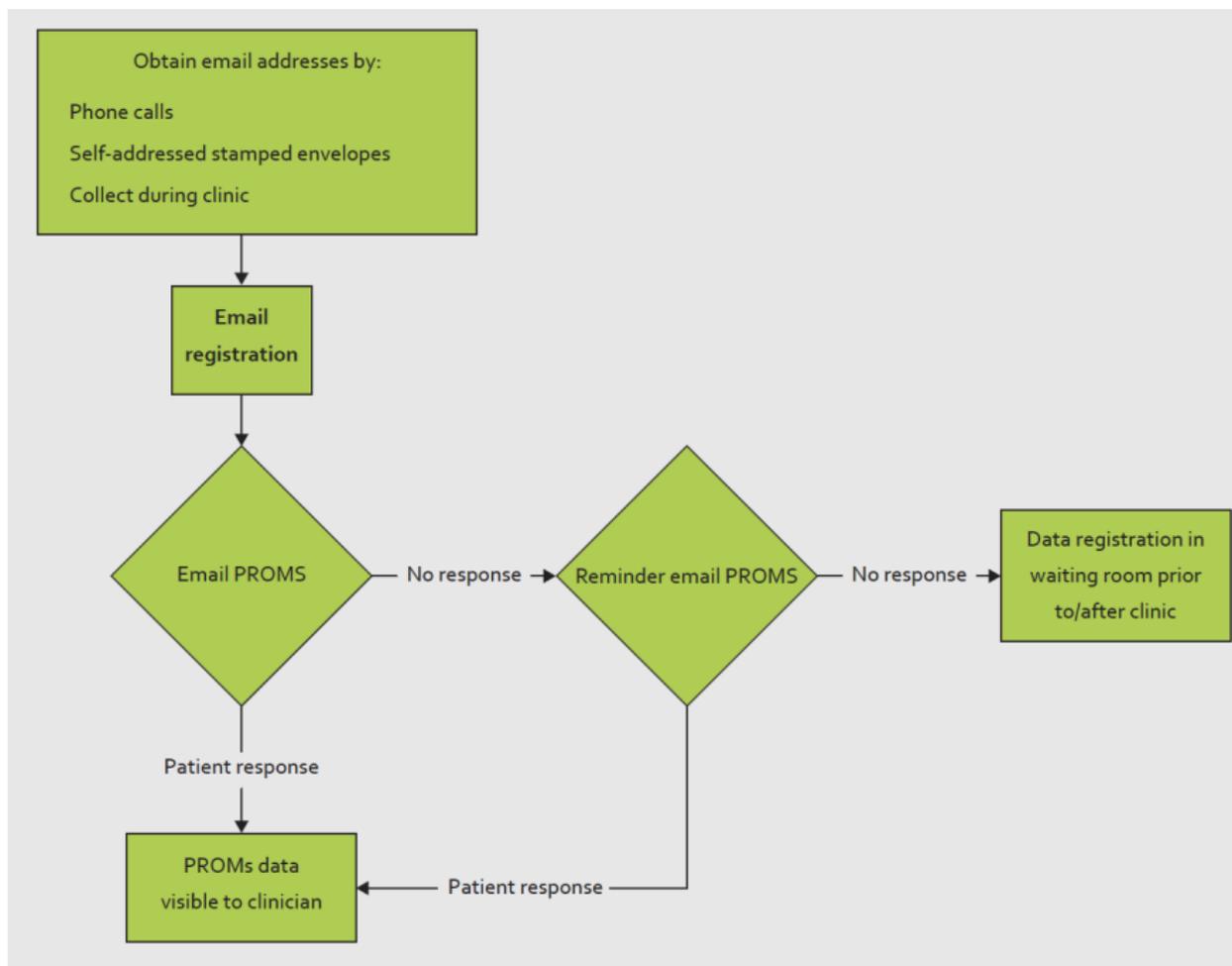


Figure 2: A flow chart describing the Erasmus CLP PROMs data collection process from registration to feedback (16)

Feedback

Feedback of outcomes data is only provided to the clinician team and not the patient directly. The multi-disciplinary team uses the information in pre-clinical meetings to discuss the best approach. Information is accessed via a bespoke software system for clinicians that integrates into Erasmus MCs electronic medical records. To develop the software, significant consultation occurred with clinicians and multiple beta models were tested. As shown below in Figure 3, the system shows the PROMs completed, those pending and whether the staff or patient is responsible for completing the questionnaire. The results of each completed survey can then be viewed.

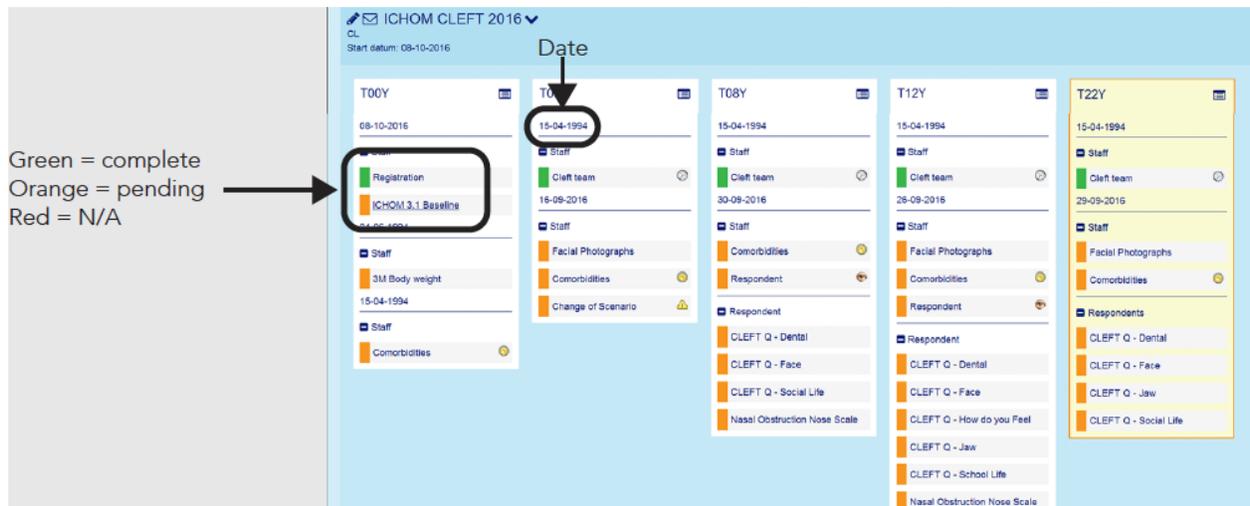


Figure 3: Screen capture from the clinician dashboard showing the schedule of PROMs. Orange and green boxes show the questionnaires that are completed or pending (16)

Strengths

- Strong resource base and institutional commitment that enabled expert informed design of the program.
- Encouraged uptake by promoting cultural change in patients alongside dedicated clinical training.
- Conducted in depth review of patient pathways and clinical flow to identify crucial intervention points for PROMs and optimise the integration of these new tools.
- Public and clinician education alongside regular stakeholder feedback is a hallmark of this program. This is particularly important when working with CLP children and their families, ensuring all parties understand the role of PROMs.
- IT platform design underpins the success of the broader program, but requires codesign with patients and clinicians.
- Integrated into electronic medical records for easy access and integration

Weaknesses

- Does not provide online dashboard system to the patients, with the data only used to guide clinician decision making at this time.
- Currently only implemented at a small scale, focussing on one condition in one institution.

Case Study 4: Stanford Health Care – Neurological Spine Clinic

The Stanford Medicine Complex in California, USA is home to the specialist academic hospital known as Stanford Health Care. Contained in this hospital is the Neurological Spine Clinic which in 2013 began the implementation of a patient reported outcomes program. The program aimed to develop a model to demonstrate the true value of clinical services, improve their quality and identify opportunities to improve performance while lowering costs. Quality of life

data had been sporadically collected in the past, but this was the first effort to consolidate the data in one location (17).

Early on, it was identified that an ideal approach for integrating PROMs may be directly through the EMR. This is a greater IT challenge than setting up a separate system, but the founding team believed adjoining it to the well-known EMR would reduce burden on clinicians and improve uptake (17). Similar to the process described at Erasmus MC, a multi-disciplinary team comprising business, IT and clinical specialists was first formed. As a group, they conducted a review of current practices to determine:

- Optimal intervention points in clinical workflow and patient care pathways
- Opportunities and ability to integrate PROMs data into EMR
- Requirements of a cross-disciplinary team and final product that met needs of business and clinicians

The review enables a more collaborative and optimised model to be produced that may cater for the many disciplines that must interact with PROMs data throughout the clinical process (18). Gaining an understanding of the clinic workflow is important because staff will be more receptive to a program that is cognisant of their needs and integrates into current practices.

Data Collection

The data collection process begins when a new patient is booked in for an appointment. The first online PROM questionnaire is emailed to patients 30 days prior to their clinical visit. They can then complete this online via the patient portal. Considerations have also been given to language or technological barriers, with patients able to complete the questionnaires with assistance on electronic tablets in the clinic (18).

However, in trials, poor completion rates occurred for at home surveys, leading the research team to allow all pre-operative questionnaires to be completed in clinic (17). Overall, this increased completion and appeared to have minimal negative effect on workflow. In clinic completion presents other challenges though, with a review noting that future steps will include designing smartphone or mobile applications that allows geographically spread patients to still complete surveys (18).

The program has a strong focus on the quality of life of the patient, particularly given the severe disability that spine and neurological patients can face. A range of different measures were used, covering depression, pain and physical disability. They include:

- Patient Health Questionnaire-9 (PHQ-9)
- Oswestry Disability Index
- Neck Disability Index
- Visual Analog Scale for pain (VAS)

Post-surgery, outcomes were collected at 3, 6- and 12-month intervals. Using the EMR, it was programmed to automatically send these scheduled questionnaires to patients. They were then given 60 days to complete the PROMs (17).

Feedback

Given the data is integrated with the EMR, feedback is currently only given to clinicians. It is hoped that clinicians will use it to inform optimal treatment approaches and then share the data

with patients during consultations. At this time, no specific mechanism has been designed for direct feedback of the data to patients.

PROMs data can be overly complex and if not presented correctly is cumbersome for clinicians to use. In response, the Stanford team opted to design a clinician facing dashboard that consolidated all information and presented it through engaging graphs. A guiding principle has been to ensure data is accessible and actionable. The dashboard allows clinicians to more readily analyse PROMs data in diagnosis and management. For the patient, the clear and customisable information available via the dashboard enables clearer and more relevant communication of data to the patient (17).

As can be seen in Figure 4 the clinician gets access to a large volume of information all recorded in the EMR. The 'Summary' tab collects the most relevant data to immediately present to the clinician. The information stored in other tabs then enables clinicians to access more detailed data on a particular area of interest such as satisfaction or pain.



Figure 4: The clinician facing dashboard. The tabs available can be seen at the top of the figure, with the different outcomes presented through multiple charts (18)

Strengths

- Effective institutional support and multi-disciplinary team ensures the program is well adapted to current practices and thus is more easily integrated into care.
- Review and analysis of the suitability of PROMs at specific time points ensures data generated is relevant to multiple stakeholders
- Multiple measures chosen to cover diverse range of patient outcomes and across many time points. This provides more accurate information on the patient and keeps them in close contact with their health provider post-surgery.

- Bespoke dashboard system designed to integrate with EMR, enabling easy uptake of PROMs into clinical care practices.
- Dashboard allows clinicians to view detailed or general information at their discretion and reduces complexity of data to make it more clinically relevant.

Weaknesses

- No direct mechanisms to provide patients with their PROMs data and personal feedback. All information is filtered through the clinician with PROMs data only viewed by patients during consultations.
- General population data not yet provided on public access websites.
- In clinic completion of PROMs is currently favoured which may increase compliance but can limit access to geographically dispersed patients.

Case Study 5: The Martini Klinik

Located in Hamburg, Germany, the Martini Klinik is one of the world's leading prostate surgery centres. Outcomes measurement is a key pillar of their success and were first recorded in 1992. Patient centred health care is at the heart of the Martini Klinik's operations, and this approach has with reported outcomes exceeding average national score. The program has led to better outcomes and lower costs, increasing the value of services the clinic can offer. It is staffed by a range of specialists who are highly educated in PROMs use and offer comprehensive patient-centred care (19). The outcomes database has been under construction since 1992, beginning with specialists simply entering surveys into excel spreadsheets. The collaborative multi-disciplinary approach is also evident at the Martini Klinik, with IT specialists, biostatisticians surgeons working together. The program is now supported by significant IT infrastructure and the system has transferred completely online (20).

Prostate surgery occurs in response to prostate carcinoma and can be life threatening and have a significant impact on the lifestyle of patients. Surgery may cause incontinence, sexual dysfunction and discomfort. As a result, spouses are included in meetings where appropriate and extensive education packages are provided to patients pre-operation. These packages provide an overview of the surgery, as well as describing the importance and application of PROMs throughout the surgical and recovery process (20).

Data Collection

Patients are first referred to the clinic, where their case will be examined by a single specialist. Surgery only occurs when broad consensus is found between pathologist, oncologists and all other specialists involved.

The outcomes recorded are based on the ICHOM standard set of outcomes for prostate surgery, with Martini Klinik specialists having been heavily involved in its development.

Baseline demographic and functional data are collected before the operation. The QL-C30 PROM is first used to document the patients emotional state. The predominant measure used is The Extended Prostate Index Composite Survey (EPIC-26) (20). It is a comprehensive PROM with 26 questions that covers continence, bladder irritation, rectal discomfort, virility, and hormone therapy side effects.

There is extensive follow up for all patients, with PROMs delivered 1 week, 6 months and then every year post operation. These PROMS are delivered by email and completed through a web-based application. This approach has been successful with a 75.5% follow up rate (21).

Feedback

The data is shared directly with health care professionals. It is used to guide surgical improvement, with an extensive review of quality conducted every 6 months. This feedback aims to further improve surgical practice to ensure that patients are able to achieve outcomes that are medically important and relevant to their desired lifestyle. Regular weekly and monthly meetings occur on smaller scales to ensure that care is constantly reviewed and improved (20).

The data is available to clinicians through the EMR. The clinic's theory of change revolves around continual clinician improvement for patient benefit and this focus means that direct patient feedback of data is not a priority (20). Personalised feedback is thus not delivered through online tools or data presentations but instead during clinical consultations. Data on complication rates and functional outcomes such as continence are presented on the clinic's website. They are used to demonstrate the quality of the clinic in these important outcome areas and provide comparisons to the national complication rates (22).

Strengths

There are many years of outcomes measurement that underpins patient centred care programs. The institution now prides itself on delivering high value care and measuring outcomes.

Long term follow-up occurs with patients and this provides extensive data on the clinic's ability to offer long term improvements to patients.

Clinicians and patients are highly educated on PROMs and their relevance to the clinical process. The delivery of education to patients at all steps is important for compliance.

Long history of outcomes measurement and use of EMR means PROMs are well integrated as a norm in clinical practice.

Weaknesses

Do not provide data directly to patients or have publicly accessible online dashboard information.

Case Study 6: Reumanet Bernhoven

Based in the Netherlands, Reumanet Bernhoven is an online personal health environment for patients with inflammatory rheumatic diseases (IRDs). The tool was developed at the Department of Rheumatology of Bernhoven, a teaching hospital in the Netherlands (23). The hospital itself has a unique institution wide patient-centred model of care. Many mechanisms are used to achieve this, integrating shared decision-making practices and PROMs extensively. Within the hospital, this trial was designed to test a potentially effective outcomes measurement and management program for patients with inflammatory rheumatic disease (IRDs) (24). It is reported that patients with chronic health challenges can have better outcomes with self-monitoring (24). As a result, the Reumanet Bernhoven tool has been developed to use PROMs in guiding effective self-management.

The online tool holds large amounts of information including basic demographic data, questionnaires and lifestyle advice. It is accessible to the patient, nurse, GP, rheumatologist and other consulting specialists upon the patients consent. Before use, patients can be provided with seminars on how to use Reumanet effectively. A key barrier to using Reumanet is poor access to internet or computer facilities, poor technological literacy and discomfort with using online tools at home. As a result, clinicians and patients must be well educated on the program to ensure all parties can extract the most value (24).

The program aims to transform clinicians into coaches, supporting the patient where they can in their own disease management. Currently, IRD sufferers require monitoring 2 to 4 times a year to assess their disease activity. With this online outpatient tool, it is hoped these visits can be reduced, and that when challenges do occur, solutions are tailored to patient need. A simple theory of self-management is applied, with research noting that patients are more likely to adhere to exercise programs if they understand the disease, can get regular feedback and have goals that they can review with the clinician (24).

Data Collection

Having registered for this program, patients are first required to attend sessions on how to use Reumanet and learn about the purpose of the system. A self-management questionnaire is used to assess their comfort with self-management practices and any potential barriers.

The patients can then begin to track their disease by completing PROMs in the online system. They are able to choose from the RAID or RADAI questionnaire. The frequency of the questionnaires is up to the patient, whether it be weekly or monthly.

More specifically, patients are asked to fill out PROMs as preparation for consultations with the rheumatologist. Basic physical data such as blood values and weight are entered as well. After 1 year the clinician and patient can evaluate management progress and address key challenges with the online system (24).

Feedback

Outcomes data and the questionnaires are accessed by the patient's personalised Reumanet dashboard as shown in Figure 5. CVRM is a measure of cardiovascular risk management and DAS28 tracks disease activity over time (24). The green cells indicate that the specific area is under control, yellow shows that it may require attention soon and red shows that it is not under control and requires further action.

If scores exceed a certain threshold, certain warnings and alerts are triggered by the system, urging the patient to address the problem or contact their clinician. This helps to identify patients whose activity is not in line with the predetermined goals and ensures they get adequate medical attention to maintain successful self-management.

Dashboard Patient

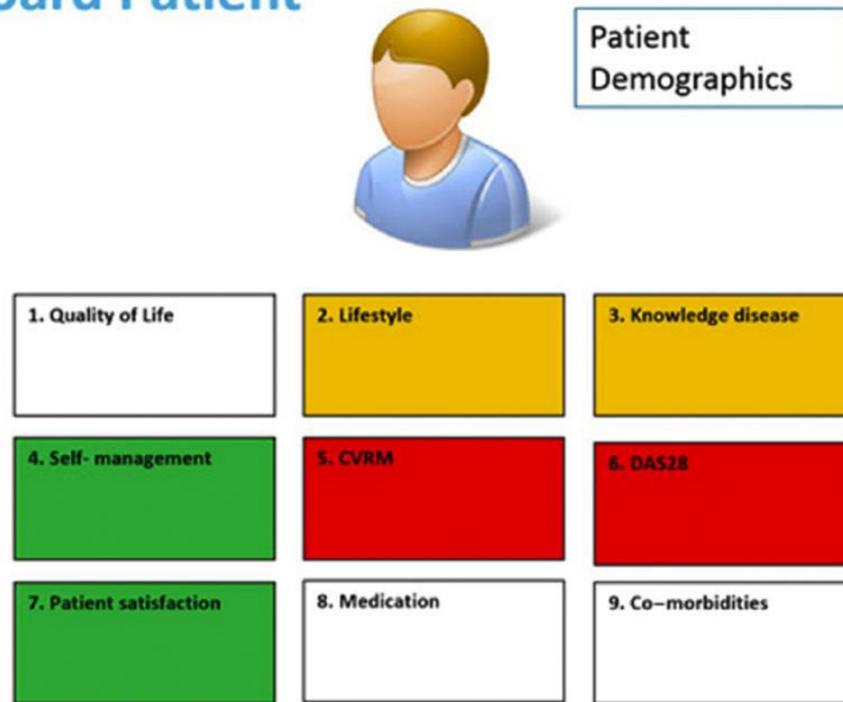


Figure 3: An example of a personalised dashboard from Reumanet (24)

Disease specific and general PROMs are used with patients also able to add self-reported data such as weight and blood pressure. The same dashboard can be viewed by patient and clinicians. Upon consultations, this ensures that clinicians are well informed of the patients' needs and can develop a suitable treatment plan in partnership. The dashboard aims to reduce these interactions though through its educational features. It provides videos, leaflets and advice on coping strategies for patients and approaches to overcome challenges in self-management practices (24).

Strengths

- Well-resourced trial that has successfully implemented PROMs into self-management
- Sophisticated online dashboard system accessible to both clinician and patient that can be used during consultations.
- Dashboard specially designed to promote self-management, integrating PROMs, warning systems and educational resources to help patients.
- Strong educational component for clinicians and patients, including lessons on how to use Reumanet and the coaching role clinicians must play.

Weaknesses

- Reliant on high technological literacy and regular access to internet facilities.
- Requires significant change in clinician's traditional role as well as changes to IT system.
- Success is dependent on patients buy in to a self-managed treatment plan.

- Each patient and clinician registering with the system requires training and
- Upskilling to understand and use system effectively.

Table 1: Summary of PROMs Case Studies from across the world

Program	Location	Feedback Mechanisms	Strengths	Weaknesses
NHS PROMs	United Kingdom	Combined general and specific measures. Online data packages released monthly alongside special reports and annual reviews.	Whole health system PROMs programme. PROMs have been used to drive efficiency and patient centred health policy. Publicly accessible data on quality of providers for patient benefit.	Minimal focus on individualised feedback. Data presented for providers and is overly complex and unengaging for patients. Feedback is generic and minimal flexibility is provided in presentation.
The Erasmus University Medical Centre Cleff Lip and Palate PROMs	Netherlands	Online dashboard integrated into EMR. Only available to clinicians Combined general and specific measures.	Disease specific system that integrates a range of PROMs across a long-time period. PROMs are complemented by education of patients and clinicians. Used in clinician team decision making.	Data is only reported to clinicians. Remains untested at larger scales.
Swedish Hip Arthroplasty Register	Sweden	Data provided through annual reports, interactive website tools and by request. 1, 6 and 10 year follow ups. Focus on clinician use of PROMs, providing significant training and resources.	Large pool of resources for clinicians. Supported by successful national quality register system that uses PROMs widely. Information that is available is well presented and interactive tools aid patient engagement.	Minimal focus on individualised patient feedback. Still operate with paper PROMs, mailed follow up and in clinic completion.
Stanford Health Care: Neurological Spinal Unit	United States of America	Clinician facing dashboard system with summary and detailed information. Integrated into EMR.	Multi disciplinary review conducted to inform design of PROMs system catered to all stakeholders. Bespoke dashboard to clearly present relevant data to clinicians. Integration in EMR increases use and ease of access.	No mechanism provided for patients to independently access individual or population data. Favours in clinic completion of PROMs, creating barriers to external completion of PROMs.
Martini Klinik	Germany	Outcomes data is shared with healthcare professionals to guide patient care. No direct data or graphical feedback is provided to patients.	Long term institutional use of PROMs that has created culture of patient centred care. Extensive follow up via online PROMs up to 10 years post op. Extensive clinician and patient education on importance of PROMs.	No mechanism for independent patient access to data. Personalised data only available through clinician dialogue.
Reumanet Berhoven	Netherlands	Uses personalised dashboard for patients that displays PROMs, outcomes data, educational resources and other health information. Clinician has access to same dashboard.	Unique implementation of PROMs to guide self-management. Reduces visits to the hospital, reduces chronic sufferers reliance on the health system and ensures the care is catered to patient needs.	Relies on technological literacy and access to internet facilities. Requires clinician's to change role to that of a coach. Success depends on patient buy in to self-managed treatment. Patients and clinicians require training and upskilling to understand and use system effectively.

Characteristics of a Successful PROMs Program

The most successful PROMs programs each share common traits despite unique designs and differing locations within the health system. In Table 1, a brief summary is shown of each case. Using the summarised information, it can be theorised that the successful PROMs programs described are characterised by the following traits:

- **Thorough clinician training.** The successful implementation of PROMs requires clinicians to be well trained on how they can be used in clinical practice. If clinicians do not actively buy in, the outcomes data cannot be discussed with a patient and more patriarchal forms of consultation arise once more.
- **Interactive public data sets.** Publicly available interactive data allows patients to enact self-management by educating themselves on expectations, complication rates and perhaps the optimal location for their operation.
- **Online PROMs collection** Collecting PROMs via paper increases burden on healthcare professionals and is less secure. Online PROMs enable access outside clinics, raises the efficiency of collection and lead to higher completion rates.
- **Review and scoping pre-implementation** Thorough research and review on the suitability and impact of PROMs on clinical flow has occurred in each of the case studies. Understanding the right intervention points and possible causes of friction in the system ensures that novel PROMs are easier for all stakeholders to engage with and learn to use.

Each case deploys tools to improve the engagement of patients with PROMs, whether it be personalised or population data. The key methods are as follows:

- **Using Dashboards** This has been found to be the major patient or clinician engagement tool used. It offers a way to filter relevant data, present complementary educational tools and allows patients access to data from their homes
- **Customisable data sets.** This enables patients and clinicians to filter through volumes of outcomes data to access only the relevant information.
- **Self-management PROMs programs still require clinicians** Engaging patients through online PROMs programs such as Reumanet are innovative approaches, but to succeed still require significant clinician attention. This is to ensure mistakes are not being made, and that patients are not left disconnected to care.

Online PROMs, eHealth and Data Engagement Strategies

Data Engagement to Drive Self-Management

Online PROMs are a specific example of how data is being used in health systems to provide a transparent care and allow patients to better understand their health. Statistics and data though are only useful to the public when they are presented clearly, accurately and in an understandable manner. For PROMs to truly promote behaviour change and self-management, literature suggests they must be presented in line with specific principles and goals.

Action and solution focussed communication of data is a key principle outlined in research on science communication, PROMs feedback and app design. Psychological science best practices suggest that positive messaging is important for actively engaging individuals (25).

Consequently, solutions must be framed in terms of what the patient can gain from immediate action and behaviour changes (25). One way that PROMs data can fulfil this criterion is via graphs that demonstrate the average change in pain or function before and after surgical intervention and recovery.

Self-management of chronic disease or surgical recovery can enable patients to increase their independence, reduce burdensome interactions with the health system and address challenges unique to their desired lifestyle. Research also suggests that those who adopt self-management strategies practise better long-term health behaviours (26). However, as found in the Reumanet trial, self-management still requires clinician assistance and a system that ensures patients are on track and able to review their data.

Exemplar studies have highlighted the broad usage of dashboards, constituting the predominant approach for presenting PROMs data to clinicians and patients. They accurately present up to date data whilst offering interactive, customisable and visually engaging information. Designing a dashboard for maximising patient self-management can be dissected into a more tailored set of rules for success. They are only basic guidelines and each program must adapt design to their target audience and the desired outcome. They include:

- Simple presentation of data
- Data focussed on possible benefits for patient
- Self-monitoring tools to induce long term behaviour change
 - Reminders and automatic follow ups
 - Accompanying information on actions required
 - Interactive and customisable features that filter and personalise data
- Simplification of complex behavioural changes into stepwise simple tasks
- Overview and specific detail options available

Elderly Data Engagement Techniques

The principles outlined inherently assume that the target audience has sufficient technological literacy to follow basic online programs. However, in the AOANJRR pilot PROMs trial, 36% of patients required assistance in filling out their online PROMs forms, with 63.8% of participating patients aged 65 or over (1). A recent report on the digital behaviour of older Australians found that 74% of people aged 70 and over were digitally disengaged, the lowest measure of digital literacy (27). Elderly patients also often have reduced trust in online services. Consequently, the poor digital literacy of the majority of joint replacement patients presents a unique barrier in the effective implementation of an online PROMs systems.

As noted in the literature review, PROMs can be completed through paper forms, or in clinic, yet these approaches can increase the burden of PROMs on the provider. A paper system that requires manual entry clearly increases workload for staff and has been identified as a key barrier to the widespread use of PROMs uptake. Electronic PROMs address such challenges as they increase the options for data presentation, reduce staff burden and promote ease of access at home (4).

Given the benefits of online PROMs systems, there must be alternative solutions provided to the question of poor digital literacy in elderly patients. Accompanying education programs such as that provided in the Reumanet trial may be one solution. Another more straightforward solution is to optimise the design and delivery of the program to ensure that PROMs are completed, and the feedback reports easy to access for those with reduced digital literacy.

- **Emphasise in communications that it is a trusted institution delivering programs and data.** This increases patient trust in the security of data and the system, enabling them to engage with the service.
- **Involve older patients in the design of online systems.** This ensures that the elderly perspective is captured in design and their average literacy considered.
- **Provide education on how to use the application.** Seminars or tutorials on how to complete forms or engage with dashboards. As older populations progressively increase technological literacy over time the burden will be reduced.

Mobile Health PROMs App Exemplar

The outlined principles for data presentation, PROMs communication and patient self-management are best highlighted in clinical trials of PROMs systems. There is no consensus method for online PROMs programs, but a case deserving examination is that of a mobile PROMs app designed for knee arthroplasty recovery. This program aligns with an increasing role for mobile apps and consumer health technology in promoting self-management.

Theoretical Basis

The program aims to use a mobile health app to promote self-management of knee arthroplasty recovery. PROMs feedback is typically provided by clinicians, but an outpatient online feedback tool allows more timely access to data for active management (28). Smartphone apps regularly deploy behaviour change techniques, with many designed to support management of diabetes, exercise and alcoholism (29). Self-regulatory behaviour change techniques are supported by an array of findings and linked to control theory which suggests that individuals can change behaviours by exerting deliberate control through goal setting and responding to feedback (29). One way suggested to enable these behaviours is through the gamification of mobile apps (29). For example, a particular study found that those who received feedback about daily step counts from activity trackers such as a Fitbit had significantly higher activity levels after hip and knee arthroplasty over 6 weeks and 6 months (30).

Program Design

Utilising this basic theory of change for self-management, researchers aimed to develop a mobile device that uses PRO feedback reports to engage and monitor recovery patients. In combination with PROMs feedback reports, the app provides education, training and access to other health information to help self-management (28).

The major challenge was determining the best design for PRO feedback reports. An extensive literature review was conducted on best practice, multiple draft versions were developed and patients consulted before final modifications were made. The research identified similar principles to those outlined previously including (28):

- Short and condensed information that uses simple language
- Use of graphs and tables that are also simple and focus attention to the most important areas.
- Colour shading of important scores and grading increases readability
- Comparison to reference populations to contextualise results

Consequently, feedback reports were constructed with data on expectations, satisfactions, physical ability and complication rates. The reports included the following features (28):

- A domain T-score
- Graphs showing reference to the norm population
- Score thresholds indicating positive or negative results
- Time scales on graph to show recovery at relevant points
- Predicted disease trajectory
- Functions to communicate directly with health care professionals
- Educational resources and information to aid self-management and data interpretation

Trial Results and Lessons

Overall, the trial had mixed results, some patients finding the report extremely useful whilst others struggled to use the technology. As previously discussed, most joint replacement patients are elderly and this is a population prone to poor technological literacy. The heterogeneity in technological skills makes the broad implementation of this app challenging. The key conclusions of the study assert that (28):

- The report was interesting but not helpful for all patients
- Design was appealing and informative
- Patients perceived it as more suitable to younger patients
- Approved of simple indicators and graphical displays
- Patients were wary of information overload

Successful Data Engagement

There is significant overlap between the principles outlined at multiple points throughout this section. From dashboard design, elderly engagement techniques and the mHealth trial a more comprehensive and precise set of guidelines can be produced as a conclusion for this section. This can then be used in further assessment of online PROMs systems as a baseline tool:

- Stepwise and easy to follow process for PROMs completion
- Patient and elderly co-design of feedback reports
- Simple dashboard presentation with abilities to view overview or specific data
- Customisable features in dashboard
- Comparison to reference population to contextualise results
- Colour shading and grading to concentrate the focus and increase comprehension
- Automatic follow up system
- Accompanying educational information explaining data, system and relevant recovery strategies for self-management

Analysis of the AOANJRR Pilot PROMs System

Previous sections have detailed best practice PROMs systems and described the key graphic and programmatic design principles for patient engagement. The purpose of this report though is to provide solutions for optimising the patient engagement and feedback reporting mechanisms of the AOANJRR's PROMs system.

Combining the principles of success presented in the exemplars and data engagement sections, Table 2 below demonstrates a rubric for assessing online PROMs programs.

Table 2: Summary of principles that qualitatively define successful online PROMs initiatives. It is based upon reviews of exemplars and data engagement practices

Dashboard Design	Data Presentation	Registration and PROMs Completion
Interactivity of program to access relevant data	Customisable data presented	Condensed and simple written information
Simple and engaging presentation upon login to dashboard	Important information highlighted and focussed	Stepwise logical process to register
Logical with easy to follow instructions	Colour shading used	Regular follow ups and automatic reminders
Ability to interact with or notify clinician/patient	Comparison to reference population	Engaging and logical design
PROMs or self-management educational information provided	Overview and detail data views available	

The PROMs systems' strengths and weaknesses will be examined to generate a set of recommendations to guide future improvement. As specific interest is given to the optimisation of feedback reporting for patients, the analysis will not examine all functions of the online PROMs platform, but focus on Dashboard Presentation of Patient Feedback Reports, Online PROMs completion and Surgeon Feedback Reports in consultations.

1) Registration and PROMs Completion

- Landing page points patients toward registration icons. Good use of colours to signal.
- The data entry for registration has easily understandable prompts and uses visual elements such as the progress bar to take patients through one step at a time.
- After initial registration, the information provided prior to completion of the PROMs could be increased in size.
- One question to consider is whether patients have easy access to clear information on the location of surgery, the presiding surgeon and the joint to replace given it is required for registration. Perhaps when patients are contacted to complete PROMs this information should be included in the email.

- The introduction to the PROMs could more strongly emphasise the benefits of these PROMs for patients.
- The additional information is not clearly segmented from the request for consent. The layout of this page could be improved to make users flow easier through stages. More precisely, the 'Who to contact' box is not separated from the request for consent. Separating it would better conclude the page and make clearer to a patient when they will give consent.
- Number of follow ups and reminders could have greater emphasis to communicate to patients that it is an engaging and interactive process.
- The PROMs questions are well presented, showing progress, using clear language and offering straightforward boxes or scales to enter information.

Dashboard Design	Data Presentation	Registration and PROMs Completion
Interactivity of program to access relevant data	Customisable data presented	Condensed and simple written information
Simple and engaging presentation upon login to dashboard	Important information highlighted and focussed	Stepwise logical process to register
Logical with easy to follow instructions	Colour shading used	Regular follow ups and automatic reminders
Ability to interact with or notify clinician/patient	Comparison to reference population	Engaging and logical design
PROMs or self-management educational information provided	Overview and detail data views available	

2) Patient Feedback Reports

- Landing page provides clear instructions and options.
- Upon clicking 'Compare Your Results', patients are presented with a list of study results. It is not engaging, nor does it provide any indication of which results are more relevant to the patient and their lifestyle.
- A key feature missing is the ability to access an overview of a patient's overall health. Instead, only the specific results are available.
- Graphs used to compare results to the population are interactive and clearly demonstrate to patient's information that is relevant to them.
- The use of colours and shading could be utilised to better demonstrate areas of success and weakness.
- A more engaging dashboard could be substituted that welcomes patients with a more visually engaging system, perhaps presenting key graphs immediately.
- The listing of all possible results to view is a form of information overload for a patient that may cause them to disengage.

- Sorting by study appears useful from registry or clinicians view but is not suited to the patient. There are opportunities to better personalise the dashboard. A personalised 'Welcome Jane Doe' message may be a simple way to more actively engage patients with the tool.
- There is high availability of information, but it is not appealing
- No supplementary information is provided on how patients should proceed if they are not happy with their results. Adding this information may help patients to use the tool more actively.

Dashboard Design	Data Presentation	Registration and PROMs Completion
Interactivity of program to access relevant data	Customisable data presented	Condensed and simple written information
Simple and engaging presentation upon login to dashboard	Important information highlighted and focussed	Stepwise logical process to register
Logical with easy to follow instructions	Colour shading used	Regular follow ups and automatic reminders
Ability to interact with or notify clinician/patient	Comparison to reference population	Engaging and logical design
PROMs or self-management educational information provided	Overview and detail data views available	

3) Surgeon Feedback Reports

- Well customised features for clinician that allow them to compare their patients' results to the national average.
- Graphs are interactive and customisable.
- Clear drop-down menus further enable clinicians to view data.
- Menu on left hand side does not appear to provide information on clinician use of PROMs. Considering the gap in clinician training on PROMs that remains this could enable more clinicians to actively take advantage of PROMs.
- Ability to view individual patient results and the clinicians' broader population are notable.

Summary

The surgeon feedback reporting and PROMs completion functions of the AOANJRR's online PROMs systems perform well. However, the patient feedback reporting requires work to become more useful and engaging for patients. Very little effort is made in the system to promote self-management or provide a direct link between the clinician and patient. Addressing this may reduce the distance and disconnection between the patient's perception of care and the data they are being presented. Given one aim of PROMs is to enable patients to better understand their health the focus on improving patient feedback reports must be a high priority.

Conclusion

The theoretical basis for PROMs is now well understood but their practical use and value for discrete stakeholders remains to be determined. This research has shown exceptional PROMs programs are already in place throughout the world. They have various purposes and designs but are all united by the desire to improve the value of care being delivered for the patient. Clinicians remain the major end user of PROMs data, with systems designed to provide information that facilitates shared decision making. Reumanet and other Health trials have shown that the online PROMs can be used to great effect in generating educated and healthy self-managing patients.

PROMs remain a novel intervention for quality improvement and research is required to understand the quantitative benefits of PROMs, the appropriate system design and whether they truly do integrate patient voices in care. Using PROMs for self-management is an even more novel area, with few large-scale trials currently underway and significantly more innovation required to design effective programs.

For the AOANJRR, this review unearths particular principles that when adhered to may truly optimise the current PROMs system. The limitations of this qualitative review must be acknowledged though, with further trials required to determine whether specific initiatives will be successful in aiding patient engagement. Nevertheless, this investigation suggests that PROMs systems must engage in more user centred design, focussing more explicitly on the patient rather than the provider or institution's benefits. Deriving from global best practice, specific interventions can create more engaging online dashboards that better communicate PROMs feedback. Design and implementation must be improved to overcome many barriers, but no matter the challenge, the simplicity and transferability of PROMs will ensure they remain at the forefront of global improvements in patient centred care for years to come.

Recommendations

Based on the findings of this report, specific recommendations for the AOANJRR can be made. Extra technical recommendations on the design of the online PROMs system can be found in the previous analysis of the AOANJRR PROMs. The recommendations and analysis process used to produce them are based only on qualitative research. To more precisely determine optimal designs for patient feedback reports and understand a patient's perspective, controlled clinical trials and extensive patient consultation are required. The below recommendations summarise actions that the AOANJRR can enact to improve engagement with PROMs and the value of feedback reporting for patients:

- 1) **Increase clinician training on the functions of PROMs data to increase usage and value.** Clinicians are the critical factor in enabling effective use of PROMs. Given the registry's unique national position, it could develop more comprehensive training material for clinicians.
- 2) **Review follow up timelines and post operation communication methods.** Many of the successful programs collect PROMs and follow up over long time periods. The longer timeline provides information on the long-term impact of the surgery and may provide technical insight on improvements. Regular follow ups may also keep patients engaged with recovery and healthy behaviour.
- 3) **Redesign the patient feedback reporting dashboard to better engage patients.**
 - Use more visual presentation of the data
 - Increase functions to view broad and specific data
 - Personalise dashboards to present relevant information

- 4) **Liaise with clinicians to build a system that allows online communication between clinician and patient regarding PROMs data.** A key issue with online systems, particularly for the elderly, is that they can feel disconnected or do not understand the purpose of the system. Having options that allow more direct communication regarding results may answer patient questions without formal consultations and by being more engaging increase use of PROMs
- 5) **Generate supplementary information for the PROMs program on uses of the data for patients and clinicians.** This should include more explicit instructions on how patients may use PROMs data in consultations. This may also include instructions on self-management. Given elderly technology challenges it may also be helpful to have availability of more basic explainers on how to use and interpret data.
- 6) **Design a tool for hospitals and providers to understand role of PROMs and aid practical implementation in their systems.** One of the most notable conclusions of the exemplars was that successful institutions extensively mapped and reviewed their clinical flow and the appropriate time to use PROMs and follow up. Developing a tool that facilitates this process may improve uptake and efficient use of PROMs in newly participating hospitals.

18. TD Azad, M. Kalani, T. Wolf et al. 2016. *Building an electronic health record integrated quality of life outcomes registry for spine surgery*. J Neurosurg Spine, 24(1):176-185.
19. M, Neubauer, *Martini-Klinik Hamburg – Competing on Quality*. heartbeat med. [Online] 28 11 2019. <https://heartbeat-med.com/en/blog/martini-klinik-hamburg/#i39ijpc9ys9hid87oo8rw>.
20. M. E. Porter, J. Deerberg-Wittram and T. W. Feeley. *Martini Klinik: Prostate Cancer Care 2019*. Boston : Harvard Business School, 2019.
21. B. Beyer, 2018. *The Martini Klinik Case Study: What benefits does measurement give to a provider?* [Presentation] Madrid.
22. The Martini Klinik. *The Martini Klinik*. [Online] 2020. <https://www.martini-klinik.de/en/for-patients/>.
23. G. Venhuizen, 2019. *Can patient centred care plus shared decision making equal lower costs?* BMJ. 8219, p. 367.
24. PLCM. van Riel, RM. Zuidema, C. Vogel, SAA. Rongen-van Dartel. 2019 *Patient Self-Management and Tracking: A European Experience*. Rheum Dis Clin North Am, 45(2):187-195.
25. S. van der Linden, E. Maibach, A. Leiserowitz. 2015. *Improving Public Engagement With Climate Change: Five “Best Practice” Insights from Psychological Science*. Perspectives on Psychological Science.
26. *Persuasive Technology for Smartphone Fitness Apps*. Kajanan, D. Yoganathan and S. 2013. Pacific Asia Conference on Information Systems.
27. *Office of the eSafety Commisioner. Understanding the digital behaviours of older Australians Summary of national survey and qualitative research*. Canberra: Australian Government , 2018.
28. K.I Fischer, D. De Faoite & M. Rose. 2020. *Patient reported outcomes feedback report for knee arthroplasty patients should present selective information in a simple design – findings of a qualitative study*. Journal of patient reported outcomes. 4:6.
29. Edwards EA, Lumsden J, Rivas C, et al. 2016. *Gamification for health promotion: systematic review of behaviour change techniques in smartphone apps*. BMJ Open 6:012447.
30. N. Van der Walt, LJ. Salmon, B. Gooden, et al. *Feedback From Activity Trackers Improves Daily Step Count After Knee and Hip Arthroplasty: A Randomized Controlled Trial*. J Arthroplasty. 33(11): 3422-3428.

13.4. Appendix 4: Discussion guides



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VAHI – AOANJRR Project:
Optimising Feedback of PROMs Data to Patients
in the Setting of COVID19-related Restrictions

Workshop 1 Discussion Summary

Example of workshop proceedings and main discussion points

Preamble

"Thank you for taking part in this research. Before we start, I can advise you that all the information obtained from these workshops is strictly confidential and any information used in reports will not be linked to your name in any way.

The reason we are conducting this series of workshops is because we are interested in gaining an understanding of your experience and preference of engaging with health information in various digital formats. Your responses will inform how the AOANJRR delivers PROMs data back to patients as well as our recommendations to VAHI on how best to engage with consumers of health information.

You are welcome to opt out of the discussion at any time.

Do you have any questions before we start?"

Broad Themes to be Explored and Prompt Questions

1. Attitudes towards learning about health conditions
(No. people who sought out health information on their disease)
 - What is your past history with joint replacement, osteoarthritis, or other health concerns? (Include a personal anecdote if you are unable to get the conversation started.)
 - What are the different formats in which you have received information about health issues you have had in the past?
 - Were you given information on what you could do to improve your health outcomes?
 - o In what format were you given this information?
 - o Did the information provided meet your needs?
 - Were you told how other people with a similar condition work to improve their health outcomes?
 - o What were you told?
 - o Did you find this useful? In what way?
 - Has anyone else in the group experienced something similar or has had an entirely different experience?

2. Engaging with health information electronically
(No. people who accessed health information electronically pre COVID19)
 - a. Pre-COVID19
 - Prior to 2020, in what format did you obtain the majority of your health information from?
 - o Can you give an example?

- Prior to COVID19, had you ever used a telephone hotline to obtain health information? What was your experience of this?
 - o Did you receive the information you were after?
 - o How effective was this in providing the information that you needed?
- Prior to COVID19, had you ever had a video consultation (for example via Zoom or Skype) with a health professional?
 - o Were you seeking information or know what to ask?
 - o Was the information useful or what you were expecting?
 - o How effective was the consultation in addressing your queries/needs?
- What was your experience of this? How effective was this in providing the information that you needed?

b. After COVID19

(No. people who accessed health information electronically post COVID19)

- When COVID19 restrictions came into place, did the way in which you looked for health information change?
 - o If yes, how?
 - o If no, why not?
- Since COVID19, have you used any online services or engaged with health professionals through online services?
 - o What kind of services?
 - o What was your experience like?
- Was there anything that surprised you about accessing health information online?
 - o Was there anything that didn't surprise you?
- What was the most positive thing about being able to access health information online?
 - o What was the most negative thing about being able to access health information online?
- Was there anything that made it harder for you to access the information needed?
- Did you feel the information was trustworthy?
 - o Why?

3. Attitudes towards seeing how your health data compares to others

(No. people who would find it helpful to know how others manage their disease)

- Are you interested in how your health outcomes compare to others in similar situations to you?
 - o If yes,
 - Can you think of what kind of information you would specifically like to see? E.g. the content?
 - Can you explain why this information would be of interest to you?
 - o If not,
 - Can you explain why this information would not be of interest to you?
- Have you sought out information before regarding how your health outcomes might compare with or others with the same health needs?

- Why yes or no?
 - Did you find it useful? In what way/s?
 - What format was it in? Would you have liked it to be presented differently? How?
4. Attitudes towards accessing health information via online dashboards
(No. people who have used online dashboards)
- a. Specifically regarding the presentation of PROMs dashboards
 - Have you used online dashboards like this before?
 - Can you think of how this compares to the dashboards you've used before?
 - What do you think of these presentations of patient data?
 - Are they easy to understand?
 - What do you like about them?
 - Is there anything that isn't particularly easy to understand?
 - What information is missing but would be of value to you?
 - What information is not necessary to be included?
 - When do you think you would access these dashboards?
 - I.e. at what point in your health experience (e.g. before or after surgery or treatment)?
 - How often do you think you would access these dashboards?
 - E.g. when would you use them more?
 - E.g. when would you use them less?
 - Is there anything that could be done to make it easier for you to access these dashboards?
 - E.g. Information on how to use them, IT skills, etc.
 - Is there anything that would prevent you from accessing these dashboards?
 - E.g. are there obstacles that you foresee to accessing these dashboards?
 - Is there anything about them that would make you not want to access them?
 - What do you perceive are the main benefits of presenting patient data in this way?
 - b. Presentation of international exemplars
 - What do you like about the way these exemplars present patient information?
 - Is there anything you don't like?
 - Is there anything that is particularly difficult to understand?
 - What would make it more appealing to you?
 - Do you have any concerns about these dashboards or the type of data that would be made available?



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Workshop 2 Discussion Guide

Themes to be Explored and Questions

1. Health information dashboards
 - Option 1 – what about the below do you like and not like?
 - o Colourful welcoming front page design giving patients different options to choose what they would like to look at
 - o Icons (pictures) on each option
 - o Lots of strong colours on front page
 - o Rigid menu on the left side of all options you can click on
 - o Under each option (e.g. Mobility) each response is shown when you click 'Next'
 - o Gives option to look at a graph and table
 - Option 2 – what about the below do you like and not like?
 - o Dashboard only shows three bits of information (graph and two numbers)
 - o Option to see more from the front page
 - o Option to choose data for individual joints in top right corner
 - o Opaque or light colour options – which is more appealing?
 - o Shows before your operation, your expected outcome and after your procedure, all this has a follow down the page option where you move the mouse down and the page will move down with the mouse.
 - o All data is available to be downloaded and printed
 - o External and AOANJRR resources available – what other resources would you like to see?
 - Option 3 – what about the below do you like and not like?
 - o Colourful welcoming front page design giving patients different options to choose what they would like to look at. Neatly presented.
 - o Ability to choose the surgery if you have had more than one joint replacement in upper right hand corner
 - More detail provided so you know which joint you're looking at
 - o Print to PDF available for each response
 - o Options for each response presented at the top
 - o Navigation on top left tells you where you are the whole time
 - o Option to see graph for each response
 - o Drop down menu for each response to do with each theme
 - Graphs
 - o Scatter graph with explanation
 - o Graph showing clearly where patient has improved and regressed
 - Infographics
 - o Colourful pie chart with number and simple explanation
 - o Pie chart with explanations in colours correlating with each number
 - Explanation videos
 - o Australian census: use of cartoon and infographics in video

- Australian Charter of Healthcare Rights: using Auslan and subtitles
- Icons
 - Human body helps to visualise which part you're reading about
 - Data presented in a simple way with icons to represent the statistic



AOANJRR

Australian
Orthopaedic
Association
National
Joint
Replacement
Registry

VAHI – AOANJRR Project:
Optimising Feedback of PROMs Data to Patients
in the Setting of COVID19-related Restrictions

Workshop 3 Discussion Guide

Themes to be Explored and Questions

1. PROMs ranking exercise
 - Why is this the order you have chosen?
 - o Why have you chosen this as number one?
 - o Why have you chosen this as second most important?
 - o Why have you chosen this as third most important?
 - o Is there anything you're not sure about?
 - o Is there anything that is particularly missing for you?
 - o Is anything not important for you at all?
 - In terms of how they are phrased, would you like to see any of them expressed differently? Or are there any that are unclear for you?
 - o Your Mobility
 - o Your Personal Care
 - o Your Usual Activities
 - o Your Pain and Discomfort
 - o Your Anxiety and Depression
 - o Your General Health
 - o Your Level of Lower Back Pain
 - o Your Pain in the Joint Being Operated On
 - o How Well You Can Use Your Joint
 - o Your Satisfaction with the Replacement
 - o How your joint problem now compares to before you had your operation

2. Health information dashboards
 - Option 1 – what about the below do you like and not like?
 - o Front page
 - Buttons at the top to access results, tips for joint replacement journey, resources, and about the joint registry
 - Welcoming message
 - Description of survey and Registry
 - Statements/data in bold
 - Menu presented in six tiles
 - Colours
 - Icons
 - readability
 - o Second page (Results Summary)
 - Menu bar at the top
 - Colours correspond to tiles on first page

- 'You are here >>'
- Title
- Description of results summary
- Graph showing improvement
 - Do you understand what this is asking?
 - Arrows
 - Percentages
 - Colours
 - Readability
 - The number of options – should all be included or just key areas?
- Third page (Pain in Your Knee)
 - Drop down menu
 - Ability at the top to go back to dashboard
 - 'You are here'
 - Text
 - Graph – easy to understand? Does the description underneath help with understand what the columns mean?
 - Do you like the traffic light colours?
 - Do you like that the final results are presented first so you can immediately see how you compare now vs before your operation?
 - 'compare with others similar to you' – is this a good way to phrase this?
- Fourth page (My Joint Replacement Journey)
 - Would you find these points useful for navigating your joint replacement journey?
 - Is there anything that is missing?
- Fifth page (Resources)
 - What do you think of the headings?
 - Is there anything we missed?
 - Do you like the summary of how each link can help you?
 - Have you used any resources that have helped you that we haven't included?
- Sixth page (About the Joint Registry)
 - Link to information on our website
 - Is this useful?
 - Is there too much information?
- Option 2 – what about the below do you like and not like?
 - Landing page of dashboard
 - Do you like the ability to click on the joint that you are looking at on the body?
 - Do you like that you can click on 'Your Results' and choose which joint you would like to look at from the dropdown as well as from going to the joint on the human?

- Does the short summary of how you can use the website explain enough how to use it?
 - What more information could we have included to explain how to use the dashboard?
 - Do you like the illustration of the human?
 - Second page (About the Joint Survey)
 - Do you like that this information is on a different page?
 - Do you like the summary of the survey? Is it simple to understand?
 - Do you like the option of a video explaining what the survey is?
 - Do you like the option to see key survey results? Do you like that they are bolded?
 - Do you like that you can access the Annual Report here to learn more?
 - Do you like that you can go and see your results for the survey at the bottom here again?
 - Do you think the tiles here are a good idea or would a link to your results be preferable?
 - Third page (your results)
 - Do you like the colours on the left hand side for each category?
 - Do you like having the menu on the left or would you prefer to have it above?
 - Do you prefer this option where the graph presents first the 'before' response? Or do you prefer to know the after first like in option 1?
 - Do you like the traffic light colours on the graph?
 - Fourth page (your results)
 - When you click on the 'compare' button on the previous page, it takes you to a statistic of how you compare with others. Do you like that it is written down like this?
 - Do you like that the colour changes when you view the statistic?
 - Fifth page (your results)
 - Do you prefer the survey options to be in the bar across the top?
 - Do you like that the options correspond colour wise with the rest of the text? E.g. 'you are here'
 - Sixth page (your results)
 - Do you prefer the survey options to be in the bar across the top?
 - Is it useful to have 'back to dashboard' at the top so you can access the other options, or would you prefer to have additional options presented in a bar at the top as well?

13.5. Appendix 5: Sample responses from the consumer representative workshops

Regarding experiences of accessing health information

I had a hip replacement and I really struggled to find information. I have a background in health and still struggled. It's hard to know what you're getting, like what replacement you're getting from the surgeon and good statistics on it.

People who are 70s and up struggle to get information. They don't have access to computers.

Regarding more information they would have liked to have had

I've had arthritis of the knee... I've had a full revision and a partial revision... I knew how to prepare by the time I went to my most recent revision. But right early on I said we need to know what is going to be the function [of the joint].

To find information regarding the [knee replacement] procedure was quite challenging, but also I found that clinicians' perspective was quite... 'shrug it off, deal with it, here's the information'. I kept pushing for more information. I wanted an informed decision-making process rather than just 'sign this form' and in fact my two experiences at the hospital were not that positive.

Regarding support at every stage of the joint replacement journey:

[We need] pointers on where you can go and what you can do. Not just rehab but places that you can go to that actually suit you as far as what you want to do [to recover]. Both for physical and online information. I would have liked to have a range of options to know where to go.

I'm very engaged. I sit on a few working groups/communities. Over the past couple of years, I've learned to ask my health provider some questions and have had it drilled into me to keep asking questions until I know what they're on about and to ask for plain English.

When I left hospital, the surgeon said that someone will come visit me at home. And they did call but until they came I didn't know from when I left hospital until that person rang me what would happen when they came. I would have like to have had more information.

Feedback regarding patient PROMs dashboard mock-ups

I like that you can access a graph or a table at your leisure.

I like the format, I think it's simple. Having it even more simple would be even better.

Pain is a good way to frame [the results]. Most people are going to have a joint replacement because they are in pain and is the number one reason people will bite the bullet and have the surgery.

13.6. Appendix 6: Study information sheet

The VAHI-AOANJRR Project used an informed opt-in consent model for consumer representative workshops. Workshop participants were provided with a study information sheet to sign prior to participating in their first of three workshops.

Participant Information Sheet

Introduction

Thank you for participating in the Victorian Agency for Health Information (VAHI) and Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR) Project: Optimising Feedback of Patient Reported Outcome Measures (PROMs) Data to Patients in the Setting of COVID19-related Restrictions.

The aim of this project is for us to learn about what works best for the general public when they review health information electronically.

Your Involvement

You agree to participate in three workshops with a small group of other people from the general public. The three workshops will be held for one hour each, outside of office hours, in the first quarter of 2021. The location of the workshops will be via web conference for participants in Victoria and, depending on participant preference, a mix of web conference and face-to-face at the South Australian Health and Medical Research Institute for participants in South Australia.

The workshops will consist of us, the research team, asking participants questions to encourage discussion about how you access health information. There will also be an opportunity for you to discuss your experiences with the research team and other participants. The research team will record the conversations and take notes throughout the workshops.

How We Will Keep Your Information Confidential

We will ensure that you cannot be identified in any reports or publications created from this research. We will treat all information from project activities as confidential and will ensure this is stored securely. If necessary, the information will only be disclosed with your permission or as required by law.

Risks and Benefits for You

There are no risks to you in taking part in this project. The information collected in the workshops will inform how VAHI and AOANJRR communicate health information with the wider community. We will also share these lessons with other health information providers. With your help you and the wider community will be more informed and have better access to health information that is useful to you.

Consenting to Take Part in the Project and Withdrawing from Research

Participation in this research is **voluntary**. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. We do ask that participants do their best to check that they are available to take part in all three workshops prior to agreeing to take part in the project. If, once you have reviewed this document, you continue to participate in the workshops, the research team will assume that you still consent to participate.

Reimbursement

The project will follow the South Australian Health and Medical Research Institute Consumer and Community Engagement Policy for Reimbursement and/or Sitting Fees of Advisory Groups. We will provide you with a payment per hour as well as travel reimbursement based on this policy. A copy of the policy will be provided to you by the research team. We will provide you with an expense claim form at the end of each workshop that you can complete to receive your reimbursement.

If you have any worries or concerns about the project or if you would like to withdraw at any time then please contact the Study Coordinator at the Registry on admin@aoanjrr.org.au or on the Registry toll free number 1800 068 419.

Participants or third parties who wish to lodge a complaint about either the study or the way it is being conducted should contact the Executive Officer of UniSA HREC in the first instance, Email: humanethics@unisa.edu.au or Tel: (08) 8302 3118 and quote protocol number 36643.

Consent

I,(full name), have read and understood the information above and consent to participate in the project.

Signature _____

Date _____