# EMR PROJECT – PATIENT REPORTED OUTCOME MEASURES

## Webinar 17th May Transcript

### Acknowledgement of Country

**Pip Brennan:** I wanted to take a moment to acknowledge the Traditional Custodians of the country that we're meeting on. This is a virtual meeting, but I'm darling in from Whadjuk Noongar Boodja here in Perth, and I'd like to pay respects to Elders past and present, and extend respect to all Aboriginal and Torres Strait Islander Peoples. I think in the issue of digital Health, as in all health issues, it's really important for us to think about the issues with a lens of our First Nations Peoples. And some of the key issues that often don't really get thought through around the cultural security of digital health.

### Recognition of Lived Experience

**Pip Brennan:** The next thing just I would just like to you know, obviously Health Consumers' Council, we believe very much in the importance of the lived experienced voice being at the decision making table at all stages at all levels. And just really to acknowledge that it is a human rights movement and with a proud history. And that we do stand on the shoulders of those who have come before us to help create the positive change that they themselves may not have been able to see. And we're obviously keen to keep I guess growing that up army of willing consumer reps who can sit at all the tables at all the levels.

### Introductions to Speakers

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| **Pip Brennan - Chair**<br>HCC EMR Consumer Ref Group Convenor | **Dr Aron Chakera,**<br>SCGH Physician, Renal Specialist, Fellow of the RACP | **Dr Christine Georges,**<br>Senior Research Fellow, Professor of Surgery at Cabrini Health |

**Pip Brennan:** Okay so just checking I don't think we have we still don't have Christine just yet. But there's me. So I'm the Chair of the Electronic Medical Record Consumer Group this has been running for about just over a year now and we've got a key interest in upskilling consumers and also influencing the Electronic Medical Record in WA. Last week, I was at the Digital Health Festival in Melbourne and it's clear that this is not something that other jurisdictions have done, so WA is leading the way in this which is great.

We do have Aron Chakera with us. He's a physician at Sir Charles Gairdner Hospital (SCGH). He's renal specialist and a fellow of the RACP.

I'm hoping we'll be joined by Christine Georges from Cabrini Health, but Aron and I said failing that, we will just carry on regardless. So if you don't mind if you could stop sharing the slides. Thank you so much.

I was actually going to get started with the questions Aron and start with you.

## Question 1. What are PROMS? [2:48]

**Aron Chakera:** Great question. So I guess at the surface level this just stands for Patient Reported Outcome Measures and increasingly- I'll just as an aside start by saying it now often includes PREMs, and you'll hear about those talked about in the same breath sometimes, as Patient Reported Experience Measures and these are not new things. So these have been used in clinical trials really for decades now. And it's about taking the patient experience and using that to help inform some of the decision making that we will undertake.

[3:21] I think there's been a number of countries that have championed integrating PROMs into the way that we deliver care really for decades now, led probably most notably by some of the Scandinavian countries and the UK, and also bits of North America as well, so centres in the US and and Canada. And that will become relevant when we talk about some of the Electronic Medical Record stuff into the future.

[3:50] So at the at the heart of these this is saying when we're trying to work out whether we're delivering care that has value clearly, the person who can work out most the value is the patient who is receiving that care.  There are some reasons which I'll expand upon in a second that extend to the system about why we would want to collect this data also. But fundamentally it's about patients reporting on their health, reporting on their quality of life and on their function.

[4:17] So I guess a really great example that came from this was from BUPA, one of the large health providers in the NHS got very engaged in PROMs from the late 90s onwards because they wanted to find out were people feeling better after they'd had their operation. So you could have, for example a technically perfect hip replacement but if the patient still had pain afterwards or had less function or they couldn't do the things that they thought they were going to be able to do, then the outcome obviously isn't the one that you wanted.

[4:48] So PROMs become a really useful tool for us to define at an individual clinician level, how are we meeting expectations, and what are those expectations, and how are things changing over time. They become quite good at a hospital level because you could start to look at variations between patient populations or individual groups and say, “well, are people getting better or worse outcomes? And what do we learn about this?” So, for example there were again cases in the BUPA and NHS example, where they looked at difference in PROM recording between different organisations, and suddenly showed a substantial improvement in hip outcomes in a particular hospital. And when they went back and [said] “oh that's a bit interesting,” they found that that hospital had introduced an intense physiotherapy program to help rehabilitate patients afterwards. And they said “oh here we go, we can see objective evidence. This is fantastic! We should now try and roll this out across the system.”

[5:45] And then I guess at a whole system level collecting PROMs gets us a better feel for what we're doing across the all of WA health, and those are things that then can start to inform policy changes.

So there’s a sort of very broad brush stroke, PROMs can allow us to do all of those things, but there is some complexity which I'm sure we'll touch on around how how you integrated and how you decide what those measures should be.

**Pip Brennan:** [6:10] Yes, so in summary Patient Reported Outcome Measures, they are really important from a consumer perspective as you say, so it's not just enough to say the surgery is done but it's important to say “were the outcomes that were important to the consumer met?”

Christine, welcome thank you so much for making the time to come along. I had very briefly introduced you, but you actually work with Cabrini Health in Melbourne is that correct?

**Christine Georges:** [6:45] Hi everyone, very nice to meet you all.

**Pip Brennan:** And am I right in thinking that oncology is your core area?

**Christine Georges:** Colorectal cancer? Correct, yes.

**Pip Brennan:** So quite specifically colorectal cancer. And are you joining us from Melbourne today or you somewhere further afield?

**Christine Georges:** Yes, very good question. So you are correct I am based at Cabrini Health in Melbourne Australia, but temporarily located in Barcelona, Spain and returning back to Melbourne in two months' time. So my background is I'm a Senior Post-Doctoral Research Fellow and I work within the Cabrini Monash University Department of Surgery at Cabrini Health headed by Professor Paul McMurrick. And for today's webinar, I'd like to kind answer some questions that you might have regarding our PROMs program that we have implemented at Cabrini Health and the Alfred which is based on improving outcomes for patients with colorectal cancer through an ePROMs platform.

**Pip Brennan:** [7:45] Yes, so I had already asked Aron the first basic question around PROMs, and we've covered that their Patient Reported Outcome Measures and with some interesting uses of the data in terms of making sure that it's measuring the outcomes that are important to patients.

## Did you have any other comments you wanted to make around the use of PROMs data Christine?

**Christine Georges:** [8:09] Yes that's a very good question. I think since we have launched our prospective PROMs program I think we can see the value in utilising PROMs, not only at an individual patient level, where surgeons are able to access the PROMs data during the consultation. And this is important because often symptom and functional concerns that patients might have following treatment are not brought into the conversation where the focus might be more so on the actual kind of surgery and the treatment outcome.

[8:44] So being able to have a platform where patients can voice their concerns really allows patients to be able to articulate where their concerns are with specific symptom and functional outcomes that they might not have thought were important to bring into the consultation. So from an individual patient perspective, there is great value in having PROMs.

[9:07] But also the ability to look at aggregated population data I think adds great value to the PROMs platform and within the Cabrini West University Department of surgery. We also have a Cabrini West Colorectal Neoplasia database which is a clinician-led database, and this database captures traditional clinical information. So the ability to combine PROMs data with clinical information maximizes the ability to then look at specific clinical questions, and address those clinical questions at a population level with PROMs data, and that can be used for research for quality improvement for benchmarking purposes. So there are kind of growing ways in which PROMs can be used to improve outcomes, not just at individual level, but also at population level.

**Pip Brennan:** And you're mentioning what the work you've been doing at Cabrini and so essentially you've got a new platform just for PROMs, have I got that right?

**[10:15] Christine Georges:** That's correct yes so we launched our PROMs platform in mid 2021 and we launched that across both Cabrini Health and the Alfred, so two major Victorian hospitals that treat a high volume of colorectal cancer patients.

So essentially, any patient that is undergoing surgery for colorectal neoplasia is invited by their treating surgeon to participate in not only the PROMs program but also in the clinical database. And once the patient consents to being involved, they then receive automated emails and SMSs that are personalised from their treating surgeon inviting them to I guess providing first information about the program and then inviting them to complete a questionnaire regarding their health-related quality of life.

[11:07] The instrument that we utilise is the ICHOM or the International Consortium of Health Outcome Measures Colorectal Cancer Standard Set. And it's quite a comprehensive standard set that has been internationally validated and deemed sensitive to determine the symptom and functional outcomes that are important to patients with colorectal cancer.

[11:20] Patients complete their PROMs at Baseline and then 6 months post-surgery, and we follow our patients up, up until 10 years post-treatment. So it's quite a long-term follow-up, and it's important I guess that we do follow up our patients long-term because often kind of at the five-year mark, when patients have follow-up, some patients might have a recurrence. So it's important that we're able to still continue to track their quality of life.

[12:00] So patients complete their PROMs, and then the data is available on a dashboard for the surgeons to view within their consultation. In addition, we also have the option for patients to view customized PDF reports and then this information is used within the consultation by the treating surgeon to identify any concerns and refer the patient to kind of various Allied Health if required like, looking at physiotherapy for pelvic floor concerns.

[12:37] And for patients if they don't complete their proms they receive automated reminders at various time points and we've found that this is quite helpful just to ensure that the patients are involved. And essentially that's kind of the PROMs program in a nutshell.

**[12:48] Pip Brennan:** Yes, that's really helpful so this is I'm really- Clare’s  put in a comment that you know, she always understood in her mind Patient Reported Outcomes to be the things that are important to consumers, but her question is

## How are PROMs developed?

I mean I have a little bit of experience as a consumer advocate, I have a little bit of experience around developing PROMs. It's not my not been my favourite, most fun activity. And I think I was really interested in a Value Based Healthcare conference I went to some time ago, about how the PROMs tools that we would call “validated” so a validated tool, and I'm just going to say this in lay-person's term and this not might not be right, but a validated tool is one that has been developed in a research context and therefore means- I mean I actually don't really know what validated - I should just ask you what it means! But, my understanding is that that you need to have the validated tools, but then they get quite long.

And then essentially, a PROM is a survey, isn't it. It's a survey that goes out, that you’ve got to fill it in and you keep filling in the similar sort of information. So really, my question is both to you Christine and you Aron, about how PROMs are made.

So I'll start with you, Christine then I'll move to Aron.

**[14:19] Christine Georges**: Yes, that's a very good question, and I think few years ago there was a review for colorectal cancer looking at the various PROMs instruments, and I think there were in that review, I think it kind of highlighted the discordance between various groups to utilize a common PROMs. And we definitely agree, that I guess if you are wanting to look at PROMs, it's important to have a set of PROMs that is deemed sensitive, and is validated for us. We've utilised the set of PROMs that comes from the International Consortium of Health Outcome Measures, ICHOM. So they are a non-for-profit organisation that create, or validate rather, a range of PROMs for various health conditions.

[15:08] And the colorectal cancer standard set PROMs was developed in combination with patients, consumers, oncologists, radiologists, medical oncologists. So there are a range of healthcare professionals and patients that are involved in validating. I think they go through a series of analyses looking at Delphi-style questions. And based on those results they deem the question sensitive for patients with colorectal cancer. And I believe that they've published that the Colorectal Cancer Standard set in a scientific journal that's been peer-reviewed and it comprises of kind of standard sets, the EORTC

QLQ-C30 and the EORTC QLQ-C29 along with specific and symptom questions that they've added into it.

[16:08] But also I guess having said that, within our group we've we recognised that the ICHOM set is a comprehensive set and at Cabrini Health we have a PROMs working group. And within that PROMs working group, we further refined the ICHOM set to include a low anterior resection syndrome score and this was because the surgeons felt that this was an important score for us to be able to capture in our patient cohort. As a result, now actually Professor Paul McMurrick and myself are part of the ICHOM Committee Steering Group. So we have now provided our feedback and I think this is taken on board in terms of the next upgrade for the ICHOM set.

[16:50] So I think that they're constantly evolving but not too much so that there's a lot of change in that people, or if the PROMs are being used for research purposes and they're wanting a comparison or even for benchmarking that that they're not constantly changing, because then it's difficult to be able to benchmark.

**[17:08] Pip Brennan:** Yes and so I just wanted to flag you Clare has already put the ICHOM link for those that are interested. https://www.ichom.org/

Some of the some of the PROMs tools that you mentioned, often you can just Google them because I get quite interested in having a look. I've experienced the Delphi Process, and what I experienced was kind of like a ginormous list of terms and you just think “oh when will this survey end!” and it sort of you sort of cut it down that way. And there's a range of different- in the project I did, it was both consumers and clinicians working through the process.

[17:47] And I think, and I guess for me that's my thing is like I've also heard PROMs described as something that's baked in a university but doesn't work in the real world and I thought I’d then throw to you Aron about PROMs, and any of your Reflections around how PROMs have created?

**[18:00] Aron Chakera:** Thanks, Pip. So I think Christine's touched nicely on some of these aspects and you know if you go online and you do decide to search for PROMs and you're setting up something ,you will come across literally thousands of different hits with every person having come up with their own version of PROMs that seems to suit what they're particularly interested in some time with their niche condition or their niche group of patients or consumers that they've looked at.

[18:32] And I don't think that's necessarily wrong, and what they're looking at may have complete utility and value for their patient population, but when it comes to that question of validity, and I think briefly mentioned in the chat just then as well around how do you then compare other groups? And if you wanted to compare your data against somebody else's data, be that locally or internationally, obviously if you're measuring the same things, that's relatively easy. If you're measuring very different things then that becomes really complex or impossible.

[19:09] So I think there is at the heart of it what are you actually trying to measure and to some degree when you make these decisions what might you be willing to compromise on as well. Because the other point which I think you mentioned very nicely, Pip, is that as a clinician or as a researcher sometimes I want to, I want answers to all of this stuff but then the burden on the patient in terms of completing those exercises, and again, we may touch on coming up, that you may disenfranchise some groups in terms of the complexity of the questions that you're asking or in their ability to complete some of the documentation, because of the stuff that you're mentioning. But if you obviously have too few bits of data then you lose some of the richness of the information that you will get.

[19:58] In general we often think about PROMs in the sort of general, generic sense and then condition-specific sense, so there are some relatively short PROMs that can be used as a kind of overarching intro into things. So for example we do in transplant clinic an annual review each month of all of our patients who've been transplanted in that month. And at the moment we are just using the it's called the EQ-5D-5L so it uses five different domains, dimension (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) and five levels of assessment within that.

[20:25] Which for us as a clinician interface is really almost an aide-memoire, you know "how are things going, I've seen your results, your transplant's working well but, oh I noticed you're having some issues with pain'" or "I noticed there's this has come up" or "you've mentioned a mobility problem and that wasn't there last year when we were looking at things. Tell me about that." So it brings that other nuance to things but it's a very simple, short-term thing and it will have nowhere near the amount of complexity that you might have around a complex colorectal surgery.

[20:59] So there are those sort of trade-offs along the way, and I think that's again at the heart of this conversation. What are you trying to measure, and what are you going to use it for? And where might you wanting to be, wanting to complete that data? And the best group of people to have that conversation with will be the patient group as well to say, "what are we going to use this for?" and "where are we trying to go with the information."

**[21:22] Pip Brennan:** So what I'm hearing is it's almost like a little bit of a balance to be struck between getting enough data for it to be useful, and creating a survey which is too burdensome for people to actually respond to, and trying to get that balance between, I guess you know quite specific conditions and I guess the thing we've got to be aware of though is not falling into the trap of “mine's different” you know because what you're saying is the more what I think I heard from both of you the more that you specialise your PROMs, the less likely you are to be able to do that thing of benchmarking. So you wouldn't be able to easily say that “oh you know that NHS Clinic is doing really well with hip replacements. What are they doing differently?” You dig down into it and surprise, surprise it's the Allied health professionals yet again, you know and you know that you wouldn't actually get that benefit.

**[22:21] Aron Chakera**. And I was going to say just on that, and again that doesn't mean that it's bad, it just depends on what that use is, you know. If it's at the clinician-patient level only, and that's all that you're interested in for the use of that PROM, then having those specific details or those nuanced questions that relate to your particular practice or the context of your practice and that condition, that's fine. Because actually, it probably isn't as applicable in other areas.

[22.46] But yes, if you want to then do those comparisons between different clinicians or different Health Services other elements, then that's when you have to have some commonality and that's where these groups that get together as you know National and International consortiums and work out “hey, what are we going to measure going forward?” become so important. And that value is that the value to that information is incredible.

**[23:07] Christine George**: Yes, I think that's a very good point I was just going to follow on with that, and I think that there is now increasing interest in kind of harmonising various standard sets for different health conditions to allow exactly that. So that there are certain questions you can pull from these comprehensive sets to allow you to then benchmark across different health conditions.

**[23:36] Pip Brennan:** Thank you. I was actually going to ask both of you, so I'll start with you Christine.

## What, if anything have you been able to do to make the PROMs a bit easier for people to fill in? What role does digitising PROMs have in this?

**[23:48] Christine George**: Yes, that's a really good question. So I guess I have experience with a retrospective study where we manually sent out invitations through the post to our patients and got them to complete a questionnaire through a link on a paper survey and or a paper invitation rather, and with that retrospective study we had a response rate of about 50%. So since then we've launched our prospective ePROMs platform which has a number of elements built into it that really has improved our response rate to now 80% and I think that that kind is partly due to the fact that it's partly due to the fact that it's an electronic platform.

[24:44] So what that means is patients will receive an invitation through their phone through an SMS or via email. They can click on a link without having to download an app. So by clicking on the link they get taken straight to the questionnaire we have emails that are personalised to the individual patient from the training surgeon. So the patient really feels that this is a communication between them and the surgeon about their quality of life.

[25:14] And they're told in the email that this information may be used to improve their health outcomes. So they understand, I guess, the benefit to them to completing their PROMs

[25:28] We also have automated in-built reminders at days three and five for patients that haven't completed their PROMs, so that helps to boost the response rate, and I think all of those elements have had a direct result in improving our response rate.

**[25:47] Pip Brennan**: Did you have anything you wanted to add to that topic Aron around making it easier for people to actually complete PROMs?

**[25:54] Aron Chakera:** Only that I'm very envious of where Christine’s managed to get to with their system so far. So for those of you who aren't in WA Health or aware of it then, many of our practice elements are still largely paper-based, and so our hospital happens to be one that is still largely paper- based, so we're reliant largely on sending out information sheets to patients which they will bring back, which is not a very efficient way of doing things. Nor is it an efficient way of then of capturing and analysing the data, which can all be done far better electronically

[26:25] When I was in a prior role, we did spend some time working with an automated system in REDCap that can do some of the similar things that have been discussed, and I think that very much is the way forward.

[26:34] And in fact there is quite a lot of data in the international literature now around the benefits of moving to an e-platform to be able to collect this for exactly the things that Christine has so nicely articulated. And you can obviously then tailor some of those communications not just to patients, in terms of addressing them, but also to languages and to formats that are obviously going to be more accessible.

[27:00] The one challenge in that space which I'll just pre-empt obviously, is there can sometimes be a bit of a digital divide, depending on your patient cohort. And you just need to then make sure that you have a mechanism so that there are not underserviced groups that are unintentionally missed from your cohort because of challenges in accessing or interpreting or interacting with surveys in that format.

**[27:27] Pip Brennan:** Yes, so I had a separate question digitising PROMs but I really feel we've answered it. I was as mentioned at the Digital Health Festival last week, and the person from the SAMSUNG hospital presented and they actually have their PROMs within their EMR, and they have something like a 85 to 90% return rate, it's like wow!

[27:56] But I wanted to pick up some questions in the chat that I wanted to go back to. One of them was, Trish had asked a question around holistic outcomes and I know that Trish you said, "I kind of misunderstood," but in a way I don't think you have.

And I just wanted to highlight it's really interesting to start googling some of the PROMs. and there was one that was mentioned about the quality of life, it was just the five questions. And as a consumer advocate I've had that opportunity of adding that into a registry - the Australasian Pelvic Floor Procedure Registry, so I think it's a really good one, Trish, to really look at the whole person. It is actually a PROM I think that really helps as Aron says, to make sure that you're really seeing the person and you're starting to see, "oh hang on a minute, this is something we need to talk about." So there's I think there's a lot in PROMs which brings me to

28:50 Clare's question was:

## How can I as a consumer how can I access PROMs data so I can make informed decisions about treatments and practitioners?

Do you want to take that one Aron?

**29:12 Aron Chakera:** Do you want me to start? All right, I'll go on with that so I think two things. One, our system is still woefully undeveloped compared to some countries and jurisdictions, where so for example, in my particular practice area of renal medicine, colleagues in the UK have Renal Patient View. So all of our patients in the UK when I was working there, they could log in and see all of their results. They can see all of the communication related to the renal care so it's all completely transparent. And obviously, I think clearly that's the sort of system that we would ideally move to. We're not quite there yet. The My Health Record to some degree bridges some of those gaps, but it's by no means complete.

29:50 I will just caveat some of those things around, obviously it's important that when that data is available generally that it's in an accessible format, and that it's interpretable. And if I look back at letters that I send sometimes, or that I receive, there often is a lot of jargon or acronyms in there. And that can create some of its own complexities, but I'll just park that component for a minute.

[30:15] And the other part of that is actually around as a consumer, if I'm using a health care system then I actually want to have data around PROMs and outcomes available to me and sadly we just do not make that available in Australia so there's been a huge body of work looking at what they call sort of discrete choice experiments and, what I mean by that. And they've done this in a whole lot of different settings so they do it you know when you go and buy your mobile phone, do you want a phone that's battery would last a little bit longer if it cost you a little bit more. How much would you pay what are those trade-offs that you would accept?

[30:51] And they've done that obviously in clinical care. Would you like to have best care that you could close to home? Of course you would, but if that's not possible, would you wait a bit longer to go and see surgeon X? Or a particular surgical unit that might be a bit further away? Or would you have different outcomes if you were happy to be seen at your local hospital?

[31:11] And consumers currently don't actually get to make that choice because nobody can see that set of data, so I think to that point. We'd love to move to a system where all of that is transparent and the hope is that that's not designed to point the finger at individuals, or particular practices, but it's designed to drive improvements in the system.

[31:30] Because people look and go, "actually, hang on. They're getting these outcomes, what do we need to do to get those outcomes?" It forces the health services to invest in the physio rehabilitation program that improves quality of life scores, because then everybody wants to be doing it. So it becomes a kind of Learning System,  and all I can say is that obviously that's the Utopia, But we are unfortunately a fair way away from that.

**[31:50] Pip Brennan:** Are you finding Christine with your digitised platform that you are able to share more PROMs data more generally with patients to help them make choices about their care?

**[32:10] Christine Georges:** Yes, that's a really good question, and completely agree with Aron's points in that I think there's an increasing move now that patients should be alerted to and be able to access their own results, and certainly that's the case for

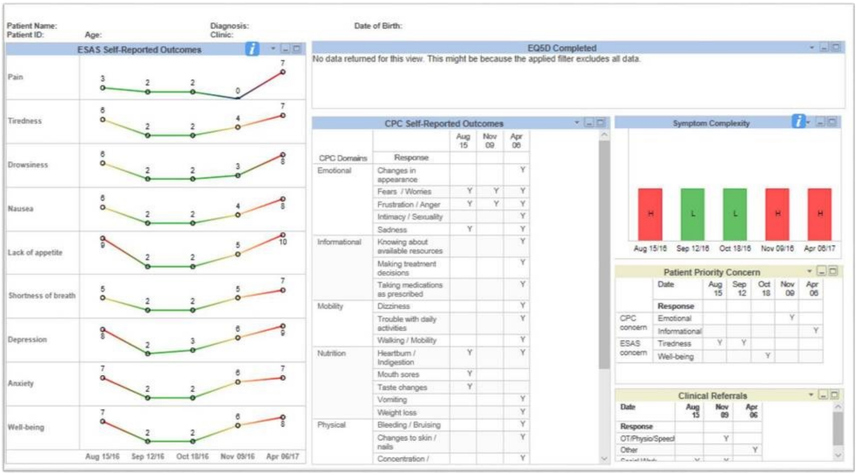
PROMs. Within our platform we have created patient PDF report summaries that patients can access. And we're in the process now of developing with our technology partners a patient portal where patients can log into a portal to be able to view their own results and see how they tracking compared to the population. So we'll combine our aggregated population data and then see how the and kind of present it in a way so that the patient can see how they sit within the population.

**32:57 Pip Brennan:** I was wondering Kieran do you think it'll be worthwhile just putting up the example Andy Steele from the EMR program he got- a couple of screenshots from Canadian PROMs on the EMR. Are you able to share that quickly Kieran?

## Benefits of PROMS in the EMR

### Standardised , easy to use and ability to trend

Patients can score their symptoms at home using the PROM , which are then mapped and visually presented for the patient.



Patient Name:
Patient ID:
Age:
Diagnosis:
Clinic:
Date of Birth:

EQ5D Completed

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CPC Self-Reported Outcomes

| | | Aug 15 | Nov 09 | Apr 06 |
|---|---|---|---|---|
| CPC Domains | Response | | | |
| Emotional | Changes in appearance | | | Y |
| | Fears / Worries | Y | Y | Y |
| | Frustration / Anger | Y | Y | Y |
| | Intimacy / Sexuality | | | Y |
| | Sadness | Y | | Y |
| Informational | Knowing about available resources | | | Y |
| | Making treatment decisions | | | Y |
| | Taking medications as prescribed | | | Y |
| Mobility | Dizziness | | | Y |
| | Trouble with daily activities | | | Y |
| | Walking / Mobility | | | Y |
| Nutrition | Heartburn / Indigestion | Y | | Y |
| | Mouth sores | Y | | |
| | Taste changes | Y | | |
| | Vomiting | | | Y |
| | Weight loss | | | Y |
| Physical | Bleeding / Bruising | | | Y |
| | Changes to skin / nails | | | Y |
| | Concentration / | | | Y |

Patient Priority Concern

| | Date | Aug 15 | Sep 12 | Oct 18 | Nov 09 | Apr 06 |
|---|---|---|---|---|---|---|
| | **Response** | | | | | |
| CPC concern | Emotional | | | | Y | |
| | Informational | | | | | Y |
| ESAS concern | Tiredness | Y | Y | | | |
| | Well-being | | | Y | | |

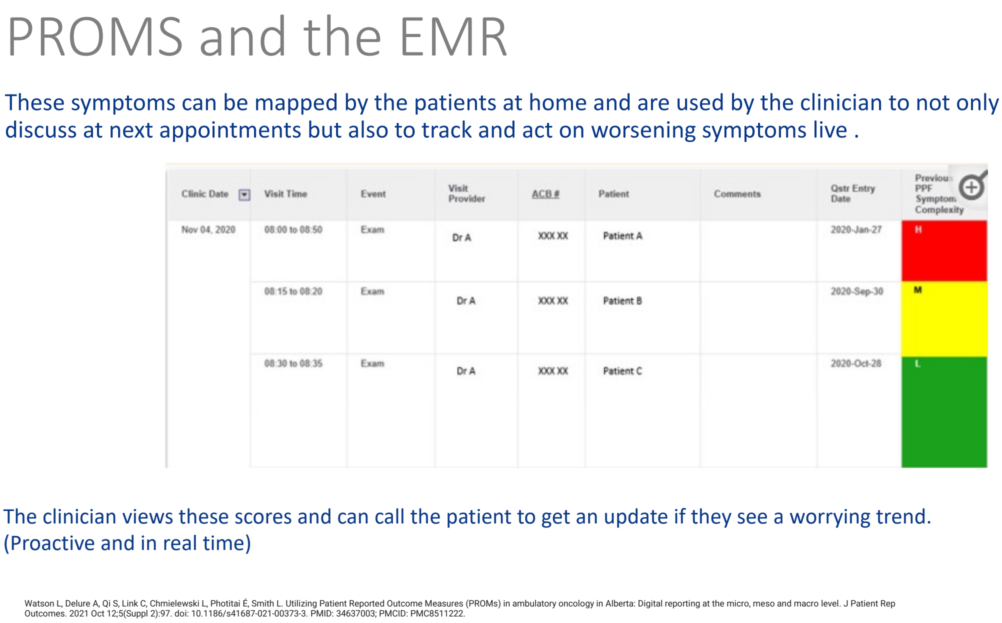
Clinical Referrals

| **Date** | **Aug 15** | **Nov 09** | **Apr 06** |
|---|---|---|---|
| **Response** | | | |
| OT/Physio/Speech | | Y | |
| Other | | | Y |

These are screenshots of patient facing PROMS screens from Alberta in Canada

So instead of it sort of being like a PDF (obviously I don't expect you to be able to read it) but in the left hand column it's got you know a thing around pain, tiredness, drowsiness, nausea, lack of appetite and so forth. And so you can obviously see it over time. And my understanding too is that it's two-way, in that patients can also complete these at home, and then the clinician can actually see things.

[33:51] I think on the next screenshot, Kieran, it actually can highlight “oh we need to reach out to this patient because things aren't right.”



# PROMS and the EMR

These symptoms can be mapped by the patients at home and are used by the clinician to not only discuss at next appointments but also to track and act on worsening symptoms live .

| Clinic Date | Visit Time | Event | Visit Provider | ACB # | Patient | Comments | Qstr Entry Date | Previous PPF Symptom Complexity |
|---|---|---|---|---|---|---|---|---|
| Nov 04, 2020 | 08:00 to 08:50 | Exam | Dr A | XXX XX | Patient A | | 2020-Jan-27 | 🟥 H |
| | 08:15 to 08:20 | Exam | Dr A | XXX XX | Patient B | | 2020-Sep-30 | 🟨 M |
| | 08:30 to 08:35 | Exam | Dr A | XXX XX | Patient C | | 2020-Oct-28 | 🟩 L |

The clinician views these scores and can call the patient to get an update if they see a worrying trend. (Proactive and in real time)

Watson L, Delure A, Qi S, Link C, Chmielewski L, Photitai É, Smith L. Utilizing Patient Reported Outcome Measures (PROMs) in ambulatory oncology in Alberta: Digital reporting at the micro, meso and macro level. J Patient Rep Outcomes. 2021 Oct 12;5(Suppl 2):97. doi: 10.1186/s41687-021-00373-3. PMID: 34637003; PMCID: PMC8511222.

**[33:58] Pip Brennan:** You can stop sharing now Kieran, but thanks so much Andy for that. So that's just an example of I guess what we're working to. Is that what you were talking, what you had in mind Christine?

**[34:12] Christine Georges**: Absolutely yes. so we have a very similar sort of a report in a bar graph or be it albeit essentially has specific domains that provide a snapshot or an overview, without kind of drilling into the specific kind of individual symptom and functional concerns. Kind of just a snapshot overview of things, like bowel function, bladder function, health related quality of life. So we've kind of just selected a few that we have in the patient PDF report. But of course if the patient wants to then delve deeper into those domains, they can through that new portal that we are in the process of getting up and running. And the in-built report alerts is also something that we are looking at  incorporating as well within the platform. And I think that it'll be very helpful then to kind of have a pathway, so that when patients are entering information and there is a significant change in a particular parameter, that that can be acted upon at the time of when that concern occurs.

**[35:26] Pip Brennan:** Perfect. So I was just going to Aron, I feel like I know of at least one set of outcomes that are publicly available I was thinking it was around palliative care or maybe it was around prostate cancer but I just wondered.

## Are you familiar with any PROMs data that is more readily available to the public?

**[35:45]: Aron Chakera:** Not locally. I wouldn't be surprised if there are some groups that are already putting some things out and I know, I think that the breast cancer cohort was working on some when Christobel Saunders was here. And that may well have been more widely disseminated. But I haven't actually seen the data sets myself.

**[36:04]: Pip Brennan:** Yes, my recollection was that it was called the CIC Cancer Project - Continuous Improvement in Care was what CIC stands for. I see, yes because that she's still involved in that I think but sadly we lost her in WA.

[36:19] Now I think what I wanted to talk about next was, how do we link PROMs? So first of all there's the idea of linking them to My Health Record. I was just wondering if either of you

## Are you aware of any work happening at a national level around PROMs and My Health Record?

**[36:41] Aron Chakera:** I'll start by saying I'm not aware beyond the fact that it it's something that I know people have been discussing. But how that gets put in and you know if you've logged into the My Health Record, where does it sit within the various reports? And if everybody is using - you know if you happen to see 15 different specialists who are using 15 different versions of your PROMs, where would they all sit in your record? I don't think there's been any answers to those sets of questions, or has there been an answer around how we address that going forwards.

[37:17] I will just shape that just again within an NHS context because even 10 to 15 years ago, they had already taken individual high priority groups. They were orthopaedics and vascular I think, and there was one other from the top of my mind I can't remember at the moment. It was this was about 2010 when they started to look at those, and they went and did a series of things where they said, “actually we're going to use these generic PROMs and we're going to use these specific ones and we're going to roll that out on a national basis as part of our-” So it's clearly doable. How that then feeds back into your My Health Record or other things, I think is a is a slightly more complex question, partly because we're already having challenges in how we get things in into that format.

**[38:00] Pip Brennan:** And for you Christine, you've been really focusing at your health service level about

The one that just belongs to your service. Is that right?

**[38:12]: Christine George**: That is a good question and, with our PROMs platform we're actually running it so that it's deliberately EMR agnostic. So our clinical database and the PROMs platform are both working independent of the hospital platform. And I guess the advantage of this is that it allows us to utilise both the PROMs and the database platforms across hospitals that may have different EMRs. And that's because sometimes EMRs can change with time, and different hospitals might have different electronic or medical record platforms.

[38:56]: And I guess that having a platform that's agnostic is important in that it means that everybody can have an equal opportunity. The software platform is available whether they are within a major hospital or outside of a major hospital, including for the patients themselves.

**[39:15] Pip Brennan:** Okay it's interesting because you know that was something I got from last week [Digital Health Festival] as well. But interoperability technically isn't as hard as all that, it's more about the culture. So that that's quite a message of hope. Excuse me, Aron you had, you were going to say something.

**[39:26] Aron Chakera:** Yes, I was going to actually echo exactly that point. And there's a comment there from Trish the headache about having all these different PROMs. And if you wanted to sit down and open up a whole lot of PDFs with different data and try and compare them, you should be there going "well you know how does 'a' equal 'b'" or whatever. But most of these sets of data sets now particularly, if you are using any sort of electronic capture system, these are coded fields.

[39:51] And you know as long as you're collecting somewhat similar information, the tools exist already to be able to do those comparisons. It's more just around as you said the culture shift to having the data there. And then who and how can the back end of that data potentially to be accessed. Because yes, you might be having 15 different PROMs that are specific for your 15 different conditions that you've got. But there probably are quite a lot of elements which are common amongst those, that could be pulled out, as long as you knew that's what you were trying to do or wanting to do.

[40:25] And again there was I think comment earlier about getting some you know retail marketing people to design the platforms. You know, these are solved issues. You know the actual technology exists to do this stuff. It's the culture and the will to harmonise and to bring it together.

**[40:43] Pip Brennan:** Yes, it was interesting Aaron you talked about REDCap as something that you've done with digitising PROMs.  Christine, I'm just curious is your platform also REDCap?

**[40:51] Christine Georges**: No it's not, it's not rEDCap. We have a third party provider the clinician and the platform is called Zedoc.

**40:58 Pip Brennan:** Sorry I'm getting a bit geeky on you, but REDCap is a platform that's used a lot in research, and I think one of those things that I've been mulling over as a consumer is that, a lot of the data that's in an Electronic Medical Record isn't very structured. And if it's not very structured, then it's a little harder to use. And my limited understanding is that REDCap can structure data quite well for research purposes. And it's you know it's essentially a survey tool, like a research survey tool that structures the data. I think I've got that right.

**[41:37] Christine Georges:** Yes, and I think it's important that if you are looking at the data and you're wanting to see it in that structured way, that the platform can provide that. And I think it's important, because if you are collecting data and then you can't collect that and visualise it in a quick, real-time way then some of the benefit of being able to look at the data is lost.

**[41:56] Aron Chakera:** And I won't go geeky on you as well, Pip, but actually you know,

**One of my other interests has been looking at unstructured data sets and how you do that.**

And again that's actually now a fairly solved problem with the AI that we have, as long as your data set is in a readable format and most of the things now can be read be they PDFs or Excel spreadsheets or whatever you can actually get data synthesised. And themes drawn out from all of those sets of data actually pretty simply.

[42:28]: The unspoken part of all of this is around, "okay, but now who can see my data? And what sensitive data is protected? How do I make sure that you know patient privacy is maintained through the system? And as Christine has built into their system hang on if somebody raises a question in a PROM that they've brought up for something else, and but they happen to see me in clinic the next day for an unrelated condition, have I got a system that will flag to me that suddenly this person's having a real problem? And that something needs and the system needs to respond in some shape or form? You know, will I get that information? How is that sort of stuff communicated? And I think that it's those areas where the real challenges will exist.

**[43:13] Pip Brennan:** Absolutely. And Kieran's just reminded us, and I was going to say at the end of the webinar too, that our next webinar is on

## Data security and trust

for exactly that reason.

[43:25] In West Australia we did do some work a wee while back. We picked up the work done in Queensland, who had developed a Consumer Digital Health Charter. We did a more specific Electronic Medical Record [Consumer] Charter and it does articulate those tensions between, you know, “I don't want people looking at my data if it's not relevant to them,” but “I would be interested in my de-identified data making our health better on a bigger scale”, and “I would also be willing for my identified data to be used if I can consent.” So there's I think you know that those sort of conversations have always happened, have already happened. And I know it's a very different thing from a consumer perspective between something in a research setting you know like in a university in a hospital, that's very different from when it's a commercial company. That's quite a different sort of undertaking in terms of trust I think. I was actually going to move onto, we've had a question.

## When is an EMR coming West Australia?

**[44:34] Pip Brennan:** So I think most people will be aware that there was a budget announcement last week. And that budget announcement has given West Australia the necessary funding for the next two to three years to get going on developing an Electronic Medical Record. As Aron has mentioned though, we are a little behind in WA, so that doesn't mean that we'll have an Electronic Medical Record in 3 years, it will mean that we'll be well on the road to getting one in those three years. But there is quite a lot of work to do behind the scenes, and WA does have a bit of time, so I think you know it's a mixed message of “yay, it's coming”, but “not in 5 seconds,” is the answer around that. Is there anything you wanted to speak to that Aron?

**[45:29] Aron Chakera:** No, only that don't hold your breath it's not coming overnight. It will take quite a while I think for this roll-out to be done across the Health Service given the complexity and size that we're dealing with. But yes we're not quite sending carrier pigeons amongst the hospitals yet to communicate. But we're still a fair way off actually having a fully functional Electronic Medical Record, although there are pockets within the system already doing this in their own way. It's just not totally joined up yet.

**[46:01: Pip Brennan:** Yes, and I think that was something I didn't fully understand, but our Chief Information Officer said “look you know we've some parts of it are have been digitised for some time.” So in a way it's sort of bringing it all together into one thing, so it's not like we're starting from absolute zero. And also West Australia has been working on digitising medical records which is not the same as a really whizbang electronic one. But you know and as Andy Steele from the EMR program has noted we're talking right across the state. so we're very lucky in WA I think to have a statewide approach. Not wanting to make you feel bad, Christine, but no statewide approach in Victoria at present.

[46:38] But you know it is a really big undertaking doing it as a statewide thing I did note Trish you mentioned something around,

## Are we learning from other jurisdictions?

The short answer is absolutely, and we are through this consumer group that gets together and talks about the Electronic Medical Record. We are specifically talking about implementation, what's that like that's going to be our final consumer meeting and we are going to hear from for example ACT and the consumer who was really involved with that implementation.

[47:21] I feel like there's suddenly a whole lot of questions. Let me just double check that I've gone through all of those.

[47:28] Also there's that when you when you mentioned that-it was really interesting what you said about unstructured data, Aron, and the use of AI. And Trish has highlighted again oh that's interesting. AI of course is something that you know potentially could mirror the biases we already have. And I guess, like all of us as consumers will be really interested to know how's

## What's the consumer involvement in AI?

So I don't know if you have any comments about that Aron?

[48:00] **Aron Chakera:** I think that's a great question, and obviously, we've seen a heap of things around biases that sneak into AI depending on, you know, how it's trained and what that data set is prime to already deliver for us. And clearly a lot of the existing data sets will be biased towards English as a first language. It will have interpretation concerns. But the nice thing about it, if our data is transparent and public, you know it's like when you put something in and it says “is this correct?” Well, you can go “actually, no, you've missed some of the point here”, or “actually, I was thinking around these things” So I don't I don't see it as being necessarily problematic, I think, as long as people can go, “actually this is the data that was generated from my comments,” and “I don't agree,” or “actually you didn't emphasise these bits correctly.” And this is what I was meaning at least on the individual level. So I think you know you can use these tools, you just need to be aware of the limitations as you put it out.

[48:56] I think the bigger concern on exactly that point is when you start to use it to look at aggregated data sets, and you don't have that individual commentary. And that is "how reflective does it become?" and "are you aware of those biases?" And look, in the first part of it is about being aware of those biases. And not treating everything that it spits out as being the absolute truth necessarily, but maybe a good starting point to go' "well here are some of the themes and here are some of the elements that have come out.

[49:25] One thing that sort of generative AI tools do well is to break lots and lots of complex data into themes. You might want to set those themes that you want to have to start with, but otherwise it will come up with the themes from the context of the information that it's given. And that's not a bad starting point when you're wanting to start, maybe drill down a little bit more to ask that question, "actually is this data set telling us what our consumers are telling us? Hey let's maybe go back to the consumers from which this data set came from, and see whether they think it reflects what it's should be doing. If not, we refine it.

**[50:01] Pip Brennan:** Thanks for that Aron

Now Christine, I'm just aware that you were only able to stay with us until the hour so that's three minutes away. I was just wondering, there was actually a question that I thought that I hadn't quite come to in the chat.

## What are the kinds of caveats (cautions) with interpreting PROMs data?

The person said "I imagine if some of the PROMs are sensitive to the point of being useful for identifying better outcomes for a condition, there might be co-morbidities that impact on some of the items but not all, but might not be captured if you're just looking at that PROM alone. So is there some issues around interpretation?

**[50:39] Christine Georges:** That is a great question and I think having PROMs as a stand-alone can show you how a patient is tracking over time, but as you've nicely highlighted, the ability to incorporate co-morbidity data with PROMs data really maximises the interpretation of PROMs results. So with our PROMs platform, we have, the Cabrini Monash Colorectal Neoplasia Database, which is a clinician-led database, which captures comprehensive information on the patient, from the stage of the cancer, the operation type and follow-up data. So there are about 300 or so data fields for each individual patient, including co-morbidities. So when we look at specific questions, we incorporate the co-morbidities and we design our research. So if we are asking a question about “what is the impact of diabetes on PROMs outcomes following colorectal cancer surgery?” we can pull that information together to really understand the impact.

[51:51] And similarly, if you're wanting to look at the outcomes for various chemotherapy treatments related to health related quality of life, the only way that you're able to do that is by pulling in clinical data to know what various treatments that patient has received, and the impact that that might have on neuropathy for example.

[52:11] So I think having that clinical data is really important in being able to ask specific clinical questions, and take into account the whole history of the patient to understand what their co-morbidities are, what surgical operation they had, so I think that that's very important.

**[52:30] Pip Brennan:** Yes, so it's really about having the PROMs in the context, of as you said, that those clinical, you talked about up to 300 clinical data fields, so that then would give you that picture. I just wanted to flag it is on the hour, so Christine if you do need to go, we'd like to thank you very much.

And Aron, I was wondering have you got more time or do you also need to leave?

**[52:53] Aron Chakera:** I have a clinic unfortunately that starts now as well.

**[53:00] Pip Brennan:** So we will farewell you both, but we'll stay online because there's some few a few other questions that are a little bit more around the consumer use [of PROMs], so we will have a bit of a conversation amongst ourselves. And Kieran's also noted that if you do have to shoot off, we'd love to hear your feedback.

[53:16] There's just one final point around;

**Colon dysfunction can lead to many neurological issues down the track, be good for collaboration with other specialities. Getting back to seeing the whole human.**

**[53:31] Christine Georges:** Absolutely, absolutely. If there are any questions or if anyone is interested in knowing further information, please feel free, I'll pass on my email details and I'm happy to catch up or have a zoom with anyone on or within a group.

**[53:49] Pip Brennan:** Thank you so much, Christine and Aron. Thank you so much for joining us. It was really great to have a chance to talk to you about PROMs. So we'll stay on the line for just, we've got some other questions that we'll continue working through from the consumer perspective but thanks again so much for your time.

# Consumer Use of PROMS questions

These questions were answered off-line, and are not part of the video.

### Q: From a Consumer representative perspective how can I use PROMs to contribute to the success of the Hospital committee?

From a committee, you can use PROMs and PREMs which will be in similar systems, to look at the services and make sure they are what people want and delivering what we want.

### Q: It's difficult for consumers who often say "I forgot to ask the doctor while I was in there." Could PROMs prompt the doctor to ask about the issue

By answering the question in a PROM, they were able to use that to guide the consultation. That's on an individual level. Over time, with digitisation, PROMs data that should enable clinicians have oversight of how patients are faring, and bring them back in earlier for treatment and/or review if they need.

### Q. With the intersects of mental health an unbelieved physical health issue, could there be solutions in this with PROMS?

As long as there are certified questions, they can be used. Security of information will of course be important. It's all about the consumers perception of how they are feeling, so it's very important for mental health, and those tools are available to monitor that. We might take that on notice as well.

### Q: Is this for hospital based-care or also community based care?

A: PROMs can really be used in any care setting. It's based around the set criteria. You can make PROMs to suit your site, but if you can

### Q. How in-depth is the consumer lived experience voice in the development of these tools? If that valued experience isn't there when we develop the PROMs, I feel like we are going to go around the same circle.

ICHOMS develop tools in many different areas of health, for use in many different health settings. There has been consumer involvement in these. Getting more and more of these measuring tools will be an important step forward.