

Evidence for PROMs in HIV care

Daniella Chilton

Guy's and St Thomas' NHS Foundation Trust, UK



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Dr Daniella Chilton

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Conflict of Interest

I have received speaker fees from Gilead, Viiv and Jansen

I have received advisory board fees from Gilead, Viiv and Jansen

I have received grants to support clinical services from Gilead

Speakers are required by the Federation of the Royal Colleges of Physicians to disclose conflicts of interest at the beginning of their presentation, with sufficient time for the information to be read by the audience. They should disclose financial relationships with manufacturers of any commercial product and/or providers of commercial services used on or produced for patients relating to the 36 months prior to the event. These include speaker fees, research grants, fees for other educational activities such as training of health professionals and consultation fees. Where a speaker owns shares or stocks directly in a company producing products or services for healthcare this should also be declared.

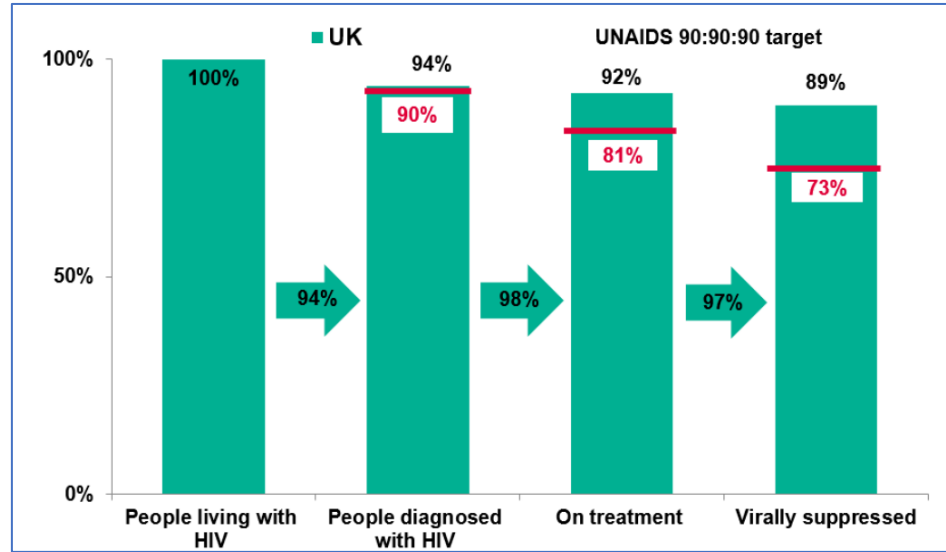
Why Use PROMs in HIV Care?

- Making care more personalised and holistic, helps us define unmet needs
- Improve doctor-patient communication on more complex issues such as mental and sexual health
- Increase commitment to self care – improving health outcomes
- Increase satisfaction in the service – pt feel 'heard'
- May even speed up an appt, if we have pre-populated information

Utility is 3-fold:

1. Essential data for pt evaluation in clinic and monitoring over time
2. Clinical decision making re pathways – stratifying care
3. At service level assess quality of care provided ?KPI for HRQOL

The 4th 90 – good health related QOL



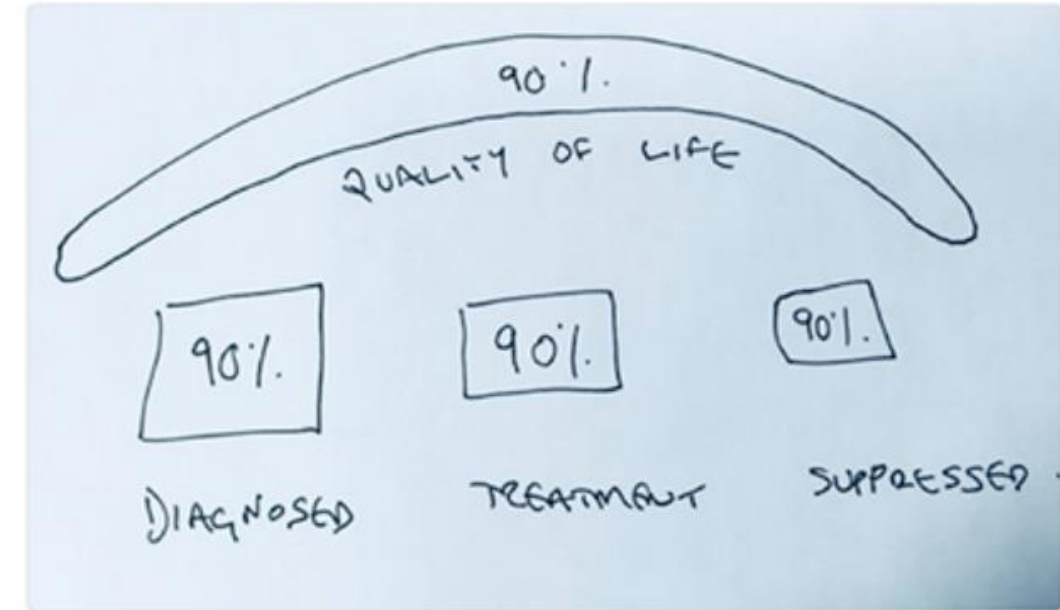
- 97% of our pt now undetectable
- Looking beyond VL to make sure that we are providing a quality service
- Service delivery promoting wellness rather than survival – the 4th 90.
- ART is a clinician-led intervention vs adopting lifestyle changes to influence co-morbidities – taking into account ability to self-manage



Tristan J Barber @tristanjbarber · Jul 25

Replying to @Positively_UK

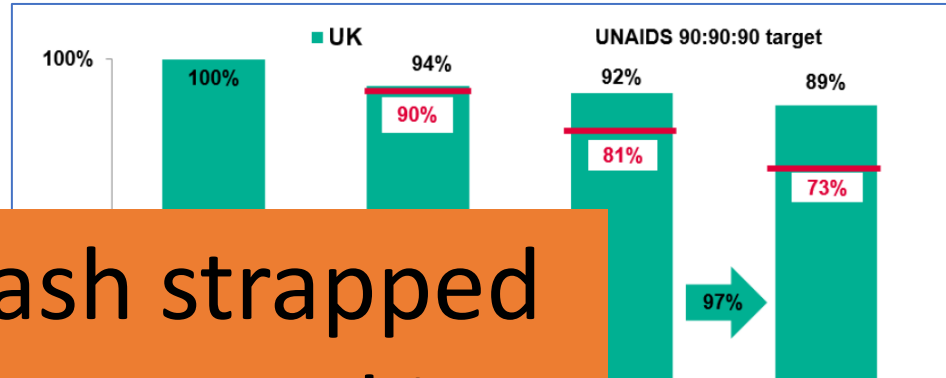
Terrible drawing but THIS is how I see the '4th 90'....



1. Lazarus et al. BMC Medicine (2016) 14:94

2. Trends in HIV testing, new diagnoses and people receiving HIV-related care in the UK: data to end December 2019 Health Protection Report Volume 14 Number 20

The 4th 90 – good health related QOL



Cash strapped
NHS – making
best use of
resources
available to us

One size does
not fit all

Personalise and
stratify the care
we give –
better for pt,
better for us

service delivery promoting wellness rather than survival – the 4th 90.

- ART is a clinician-led intervention vs adopting lifestyle changes to influence co-morbidities – taking into account ability to self-manage



Tristan J Barber @tristanjbarber · Jul 25

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90%
DIAGN

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2. Trends in HIV testing, new diagnoses and people receiving HIV-related care in the UK: data to end December 2019 Health Protection Report Volume 14 Number 20

What's important to our patients?

- Mental health
- Obesity management
- Loneliness and isolation
- Managing long term conditions – 1/3 living with 2 or more co-morbidities in addition to HIV
- Welfare needs – housing, employment, benefits applications



1. M Kall, C Kelly, M Auzenberg, and V Delpech. **Positive Voices**: The National Survey of People Living with HIV - findings from the 2017 survey. January 2020. Public Health England: London.
2. Bailin SS, Gabriel CL, Wanjalla CN, Koethe JR. Obesity and Weight Gain in Persons with HIV. *Curr HIV/AIDS Rep.* 2020 Apr;17(2):138-150. doi: 10.1007/s11904-020-00483-5. PMID: 32072466; PMCID: PMC7719267.

What's important to our patients?

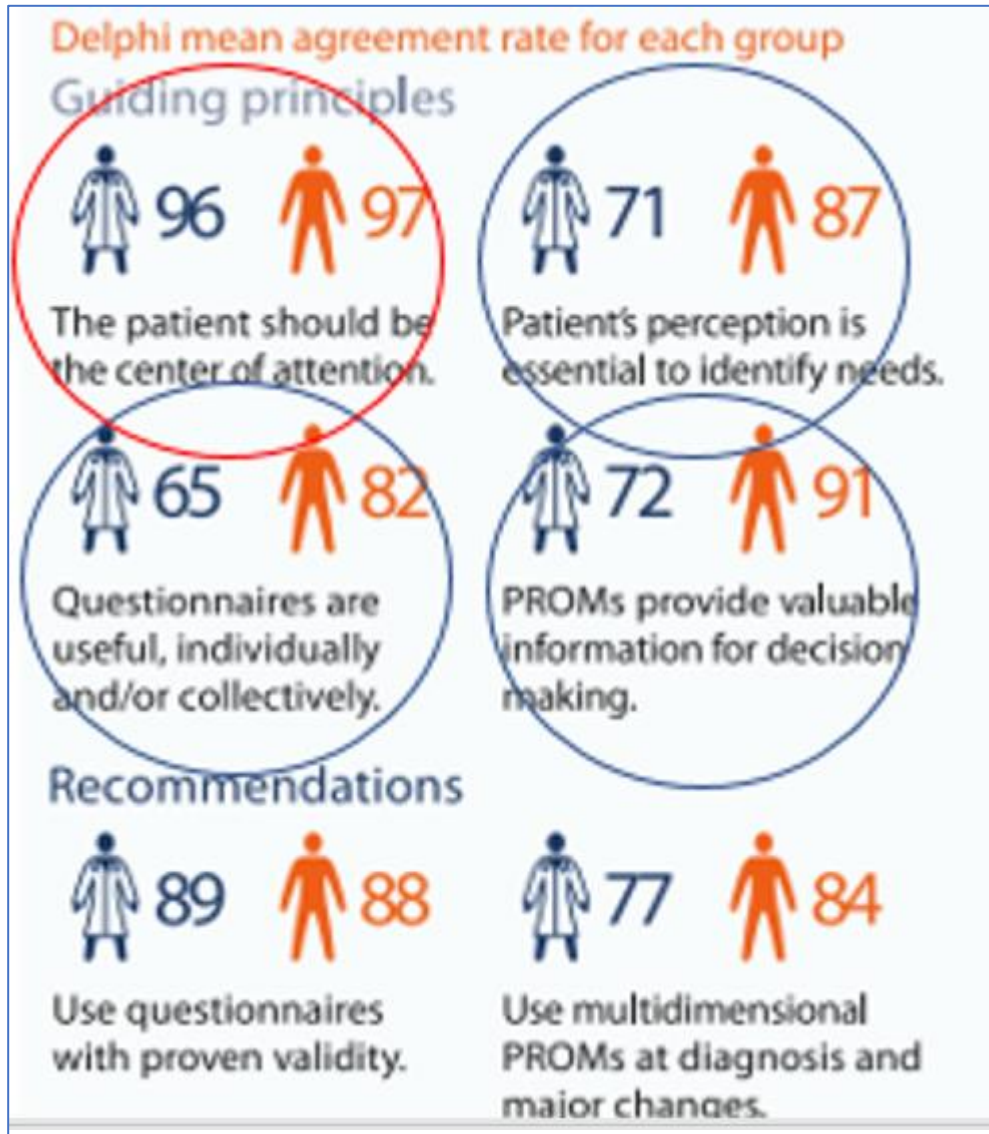
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We need to ask the right questions
to understand unmet needs -
PROMs can help us

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2. Bailin SS, Gabriel CL, Wanjalla CN, Koethe JR. Obesity and Weight Gain in Persons with HIV. *Curr HIV/AIDS Rep*. 2020 Apr;17(2):138-150. doi: 10.1007/s11904-020-00483-5. PMID: 32072466; PMCID: PMC7719267.

Pt vs clinician perspective on PROMs



We all agree that the patient should be at the centre of the consultation

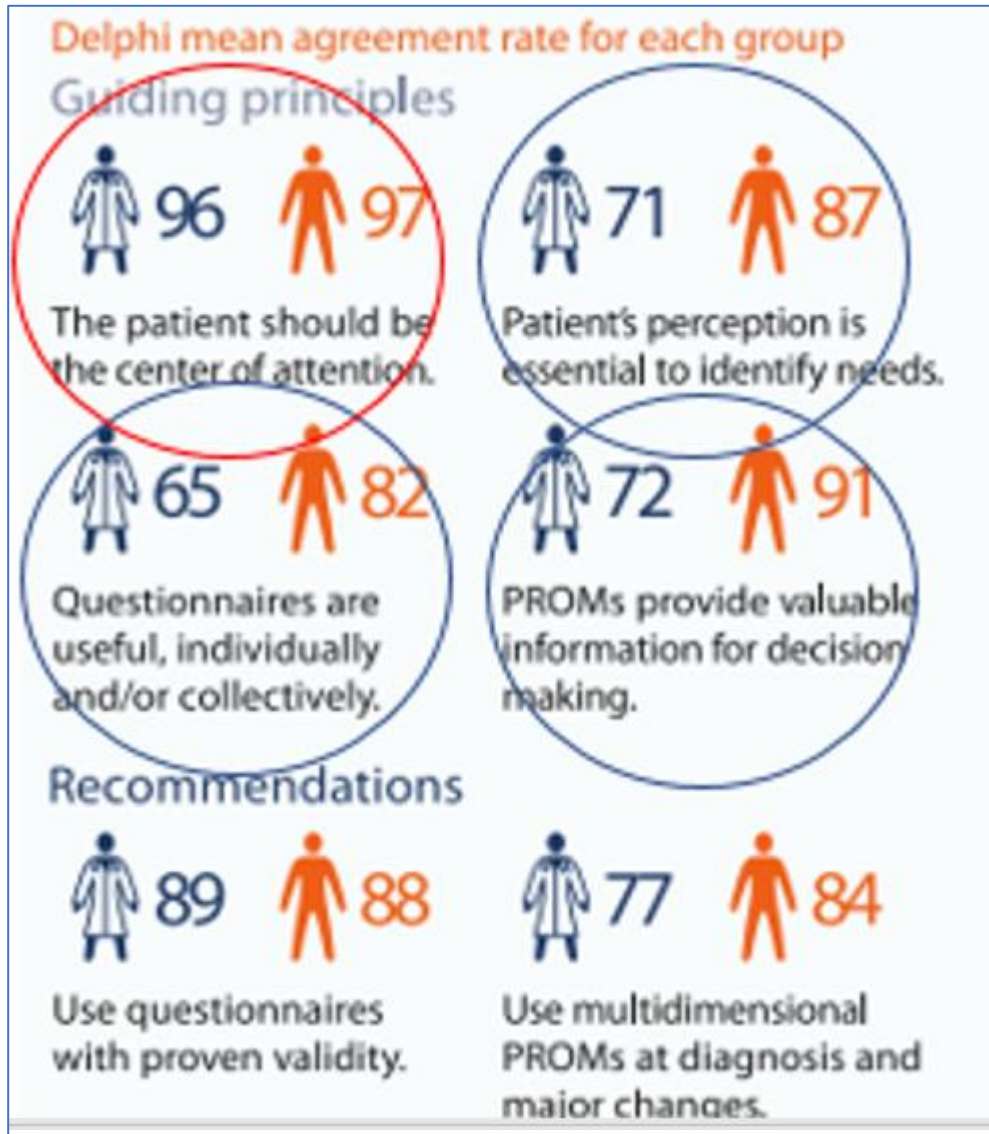
Patient perspective:

- PROM should be brief, clear, concise with some open ended questions
- They allow for more personalised care
- Training for completion is important as some questions complex

Antela A et al, Patient-Reported Outcomes (PROs) in HIV Infection: Points to Consider and Challenges
Infect Dis Ther, 2022;11:2017-2033

Greenhalgh J et al, J Patient Rep Outcomes. 2018 Sep

Pt vs clinician perspective on PROMs



We all agree that the patient should be at the centre of the consultation

Clinician perspective:

- There's no time in clinic to look at the outcomes
- Support staff should be administering PROMs
- Training for completion is important as some questions complex

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Infection: Points to Consider and Challenges
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Which HIV PROM?

- MOS-HIV
- WHOQOL-HIV
- PROQOL-HIV
- MQOL-HIV
- POZQOL
- CEAT-HIV
- Positive outcomes HIV PROM

PROQOL-HIV-EN | Questionnaire Quality of life and HIV

Instructions: This questionnaire asks you how HIV and its treatment have affected your health and your life. For each of the following questions, please check the box best suited to your personal situation. When you don't know how to reply, give what you consider to be the most appropriate answer. We want you to think about your life during the last two weeks. Make sure you answer each question by checking a single box for each line.

Very good Good Fair Poor Very poor

During the last two weeks, my overall health (both HIV and non-HIV related) has been

During the last two weeks, because I am HIV positive...

Never Rarely Sometimes Often Always

I have felt tired

I have had difficulty sleeping

I have had difficulty concentrating or paying attention

I have had problems with my memory

I have had difficulty with daily activities

I have had difficulty with strenuous physical activities such as carrying heavy running, or walking a long distance, climbing several flights of stairs

I have vomited



The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F50.1)	How much are you bothered by any physical problems related to your HIV infection?	1	2	3	4	5
		1	2	3	4	5
		1	2	3	4	5
		1	2	3	4	5
		1	2	3	4	5
		1	2	3	4	5

4. Over the past 4 weeks, how much have you been affected by **pain**? This could include headache, joint pain, neuropathy (which might include pins and needles or burning pain) or any other pain in your body

Not at all	Slightly	Moderately	Severely	Overwhelmingly
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

18. Over the past 4 weeks have you been worried about your **immigration** status?

Not at all	Occasionally	Sometimes	Most of the time	Always
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

19. Over the past 4 weeks have you felt that you have had enough **support from people around you**? This may include partners, friends, family, support groups and other networks.

Always	Most of the time	Sometimes	Occasionally	Not at all
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

To name a few!

Generic PROMs

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about	<input checked="" type="checkbox"/>
I have some problems in walking about	<input type="checkbox"/>
I am confined to bed	<input type="checkbox"/>

SELF-CARE

I have no problems with self-care	<input checked="" type="checkbox"/>
I have some problems washing or dressing myself	<input type="checkbox"/>
I am unable to wash or dress myself	<input type="checkbox"/>

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

I have no problems with performing my usual activities	<input type="checkbox"/>
I have some problems with performing my usual activities	<input checked="" type="checkbox"/>
I am unable to perform my usual activities	<input type="checkbox"/>

PAIN/DISCOMFORT

I have no pain or discomfort	<input type="checkbox"/>
I have moderate pain or discomfort	<input type="checkbox"/>
I have extreme pain or discomfort	<input checked="" type="checkbox"/>

ANXIETY/DEPRESSION

I am not anxious or depressed	<input type="checkbox"/>
I am moderately anxious or depressed	<input checked="" type="checkbox"/>
I am extremely anxious or depressed	<input type="checkbox"/>

- Allow us to compare with other LTC
- EQ5D simple, quick, free – scored to enable look at changes over time in person and potentially across services
- Less meaningful in HIV?

No clear steer on which PROM is best
Good if its validated in PLWH

Measuring ability to self-manage: Patient activation measure (PAM)

- 13 point questionnaire
- Scored via algorithm
- PAM levels indicate:
 - Empowerment
 - Readiness to take charge of their health
 - Readiness to make changes

Higher PAM = Better outcomes

Tailored interventions can
increase activation

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others want you to say.

If the statement does not apply to you, circle N/A.

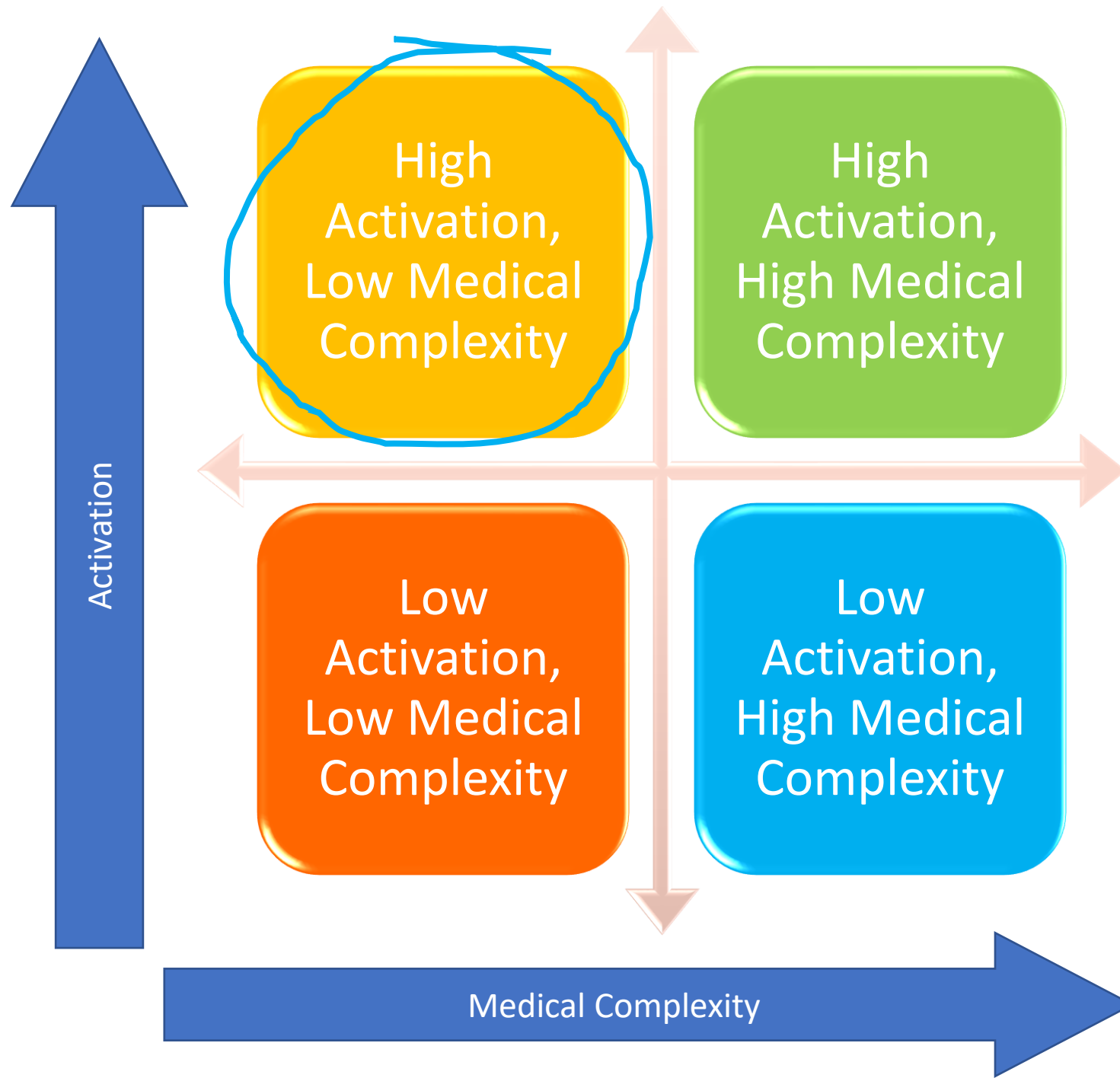
1. When all is said and done, I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2. Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3. I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4. I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

Kinney RL, et al. Patient Educ Couns. 2015 May;98(5):545-52

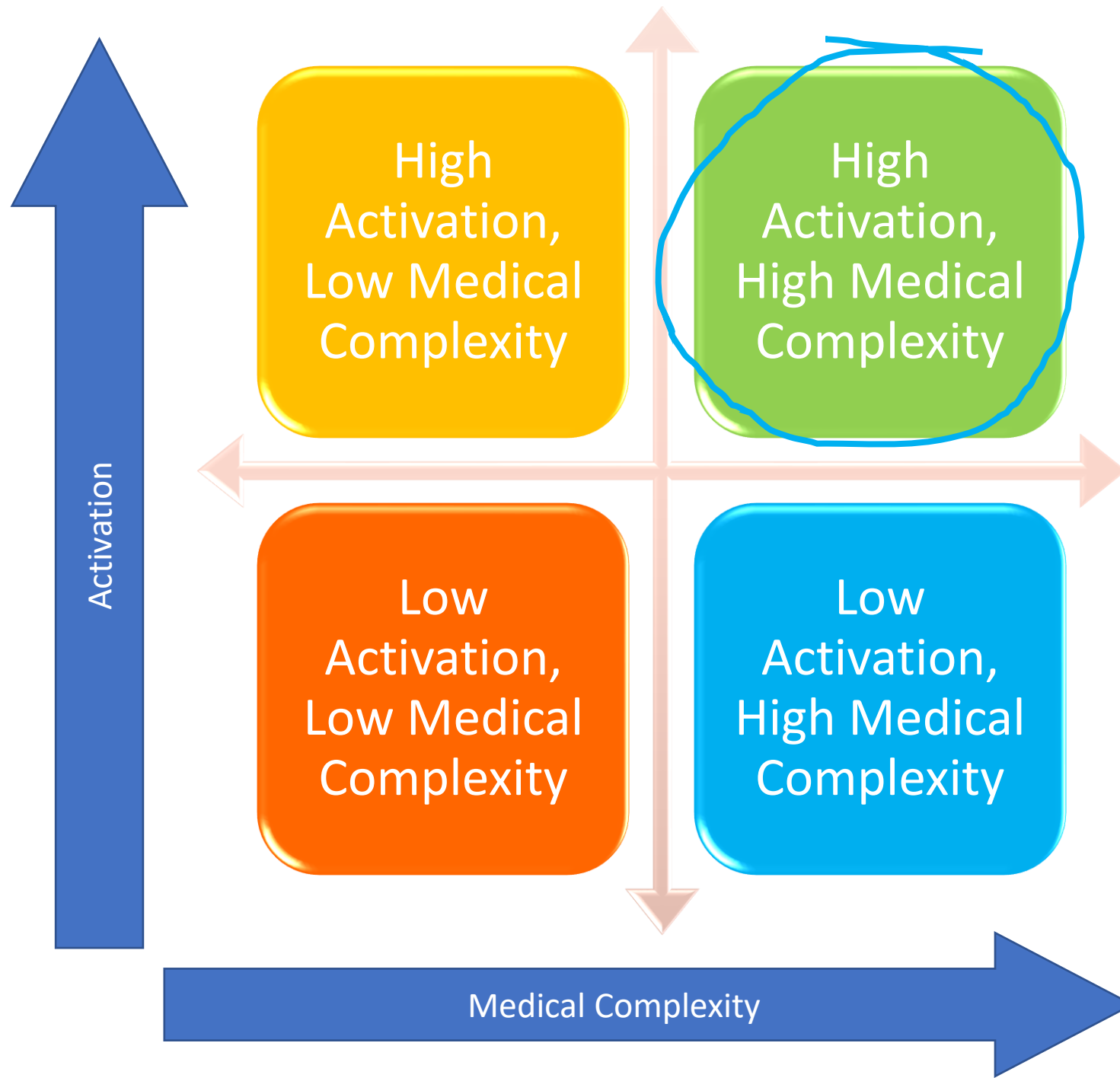
Mosen DM, et al. Is patient activation associated with outcomes of care for adults with chronic conditions? J

Ambul Care Manage. 2007;30:21-29

Hibbard JH et al. Res Brief. 2008:1-9



- Stable patient pathways
- Reduced monitoring
- Non-F2F – email / video / Tel
- Light touch support
- Screening / prevention



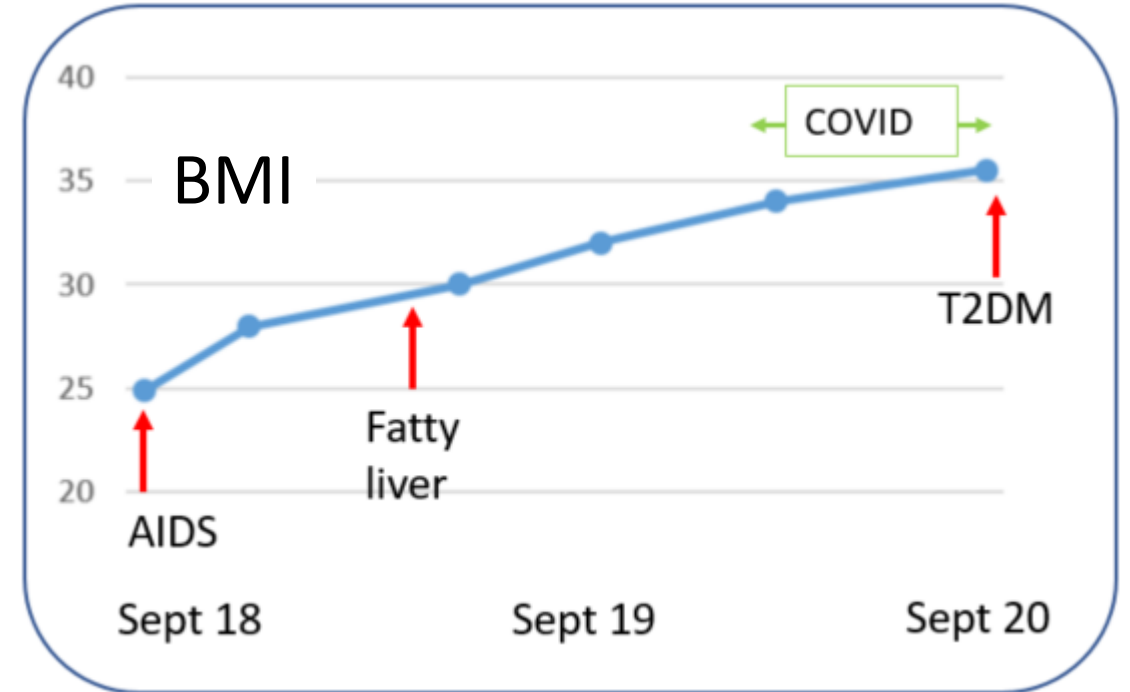
- 1 to 1 coaching
- Group work?
- Higher intensity FU
- Lifestyle interventions
- Bigger goals

Case: PJ – return to health and more

- Presentation with PCP
- Likely long hx untreated HIV
- ART - VL <20

■ But....

- Wt increase from 75-105kg
- Fatty liver
- Hypertension
- COVID pandemic – WFH
- T2DM
- Body image
- New diagnoses



PROMs and PAM can help identify what's important to PJ and what the levers for motivation might be to support him to make changes



Tailored consultation, medicines optimisation, identifying tangible risk factors, liaison with GP and other specialists



Dietary advice and education, anthropometry, referral into obesity management programmes, personalised goal setting



Clinical measurement: waist, height, weight, BMI, BP, fibroscan

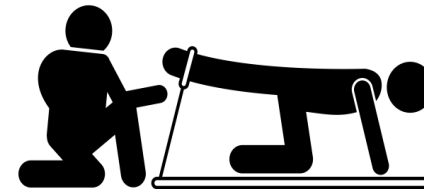
Living well clinic intervention



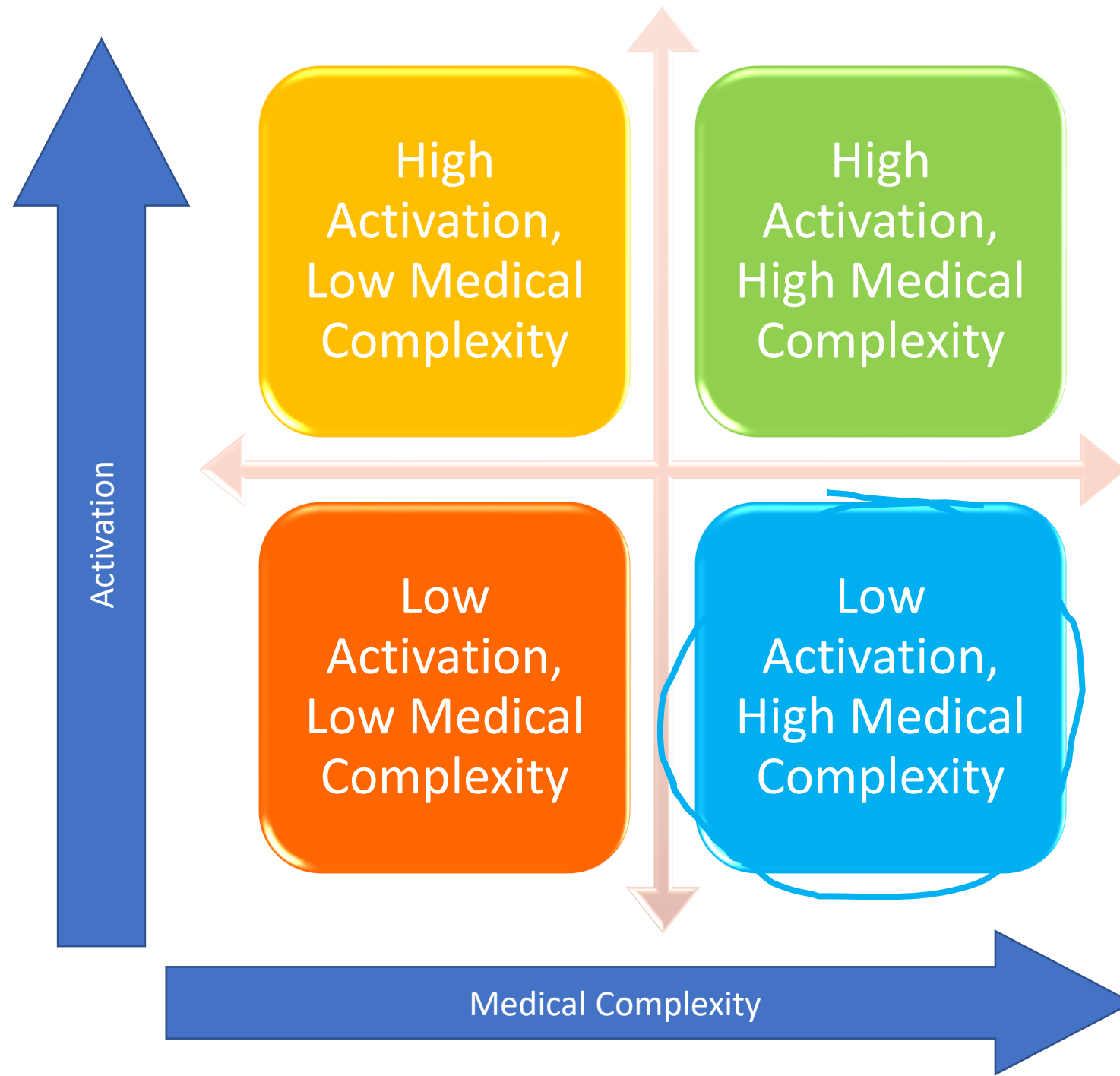
Pre-clinic PROM and PAM, motivational interviewing



smoking cessation



Exercise planning, education, personalised goal setting



- L2FU / DNA case work
- 3rd sector organisations
- Peer support
- 1 to 1 coaching
- Case management
- Group work
- Smaller goals

Summing up: Using PROMs to personalise the care we give

- PROMs support us in discovering unmet needs in clinic
- Scoring helpful in monitoring pt and services over time ?KPI for HRQOL
- Taking into account ability to **self-manage and empowering pt**
- Using tools to stratify care
 - Personalise the care we give – better outcomes
 - Utilise resource wisely, redirect resources where needed
- Developing pathways / signposting for unmet needs
- Reaching for the 4th 90!

...BUT...

- Which PROM?
- Barriers to overcome

