School of Sociology and
Social Policy

UNIVERSITY OF LEEDS

How, why and when do PROMs improve patient care? Findings from a realist synthesis

Dr. Joanne Greenhalgh

@Greenhalgh_Jo

j.Greenhalgh@leeds.ac.uk

Acknowledgements

UNIVERSITY OF LEEDS

Functionality and Feedback: a realist synthesis of the collation, interpretation and use of PROMs data to improve patient care is funded by National Institute for Health Research Health Services and Delivery Research Programme 12/136/31

The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR Programme, NIHR, NHS or the Department of Health.

Name	Expertise	Affiliation
Joanne Greenhalgh	Realist methods/PROMs	University of Leeds
Sonia Dalkin	Realist methods	University of Leeds
Kate Gooding	Realist methods	University of Leeds
Ray Pawson	Realist methods	University of Leeds
David Meads	Health Economics	University of Leeds
Judy Wright	Information Specialist	University of Leeds
Elizabeth Gibbons	PROMs/nursing background	University of Oxford
Nick Black	PROMs/policy	London School of Hygiene and Tropical Medicine
Chema Valderas	PROMs/GP	University of Exeter
Liz Lingard	Consultant Epidemiologist	NE Quality Observatory System
Jane Jackson	Nurse	JJ Consulting
Laurence Wood	PPI representative	Leeds

PROMs use in healthcare settings

UNIVERSITY OF LEEDS

Aggregate level

- Data collected from patients before & after procedure
- Adjusted for case mix
- Aggregated at hospital level

National PROMs programme (England)

Individual level

- PROM completed prior to clinician visit
- Fed back to clinician during visit
- Data discussed in consultation

Or

- Used to decide if follow up needed

eRAPID (UK)

KLIK (Netherlands)

AmbuFlex (Denmark)

Existing systematic reviews (circa 2015)

Cochrane style reviews in any setting	**Cochrane style reviews in:**
Greenhalgh and Meadows (1999) Espallargues et al (2000) Gilbody et al (2002) Marshall et al (2006) Valderas et al (2008) Carlier et al (2010) Boyce and Browne (2013) Gonclaves et al (2016) - protocol	Gilbody et al (2001) Lambert et al (2003) Knaup et al (2009) Carlier et al (2012) Krageloh et al (2015) Kendrick et al (2016) **(2) oncology/palliative care** Luckett et al (2009) Chen et al (2013) Khalid (2013) Mitchell (2013) Kotronoulas et al (2014) Howell et al 2015 Etkind (2015)
Qualitative reviews Duncan and Murray (2012) Boyce et al (2014)	**Mixed methods** Greenhalgh et al (2005) Antunes et al (2013) Etkind (2015)

What is Realist Synthesis

UNIVERSITY OF LEEDS

- Literature review methodology (Pawson 1996)
- Interventions not universally successful – impact often varies depending on context
- Explores how, why and when interventions work ('***what works, for whom, in what circumstances***') rather than 'does this intervention work or not'
- First – identify how and why intervention is intended to work – called '**programme theories**'.
- Programme theories expressed as hypotheses to be tested– "in this situation (context), the programme works in this way (mechanism) and produces these outcomes" – call it a ***CMO configuration***
- Second - programme theories tested by identifying relevant empirical studies – does as expected in practice? If not, why not? How can we improve our explanation?

Our review: an overview

UNIVERSITY OF LEEDS

Identify theories

- Search to identify programme theories
- Developed a model of how the intervention intended to work
- Selected programme theories to test in collaboration with patients and stakeholders

Search for evidence

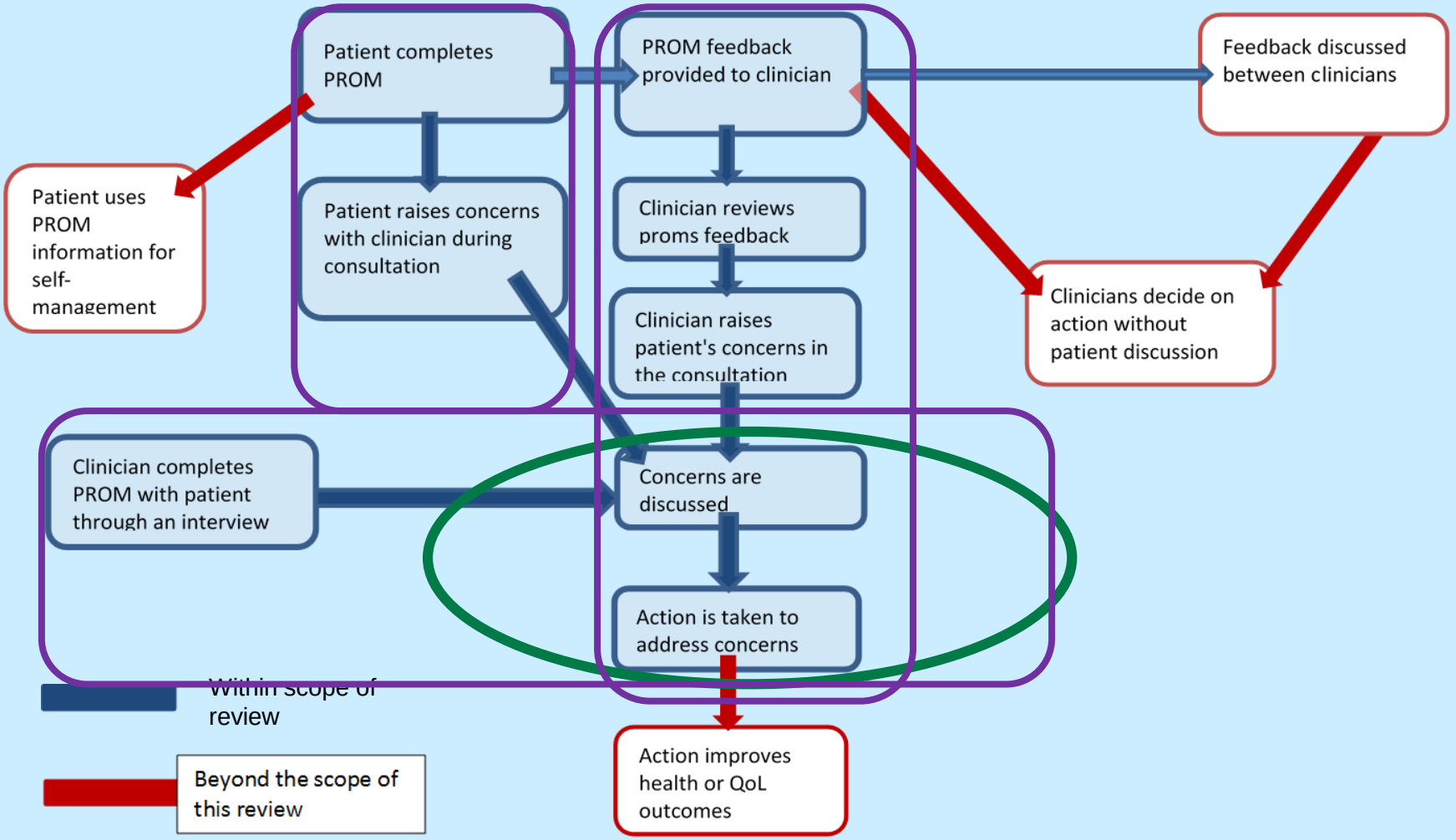
- Backwards and forward citation tracking of six key papers and five systematic reviews
- 977 papers, 159 included as title/abstract, 42 included after full text review – 23 included in analyses presented here (theory 1)

Theory testing and refinement

- Tested two main theories with 10 ‘sub theories’
- Data abstracted into evidence tables and used to test and refine theories
- Comparative analysis of across different settings

Pathway through which PROMs can improve patient care

UNIVERSITY OF LEEDS



Initial Programme Theory

UNIVERSITY OF LEEDS

Theory 1: PROMs completion enables patients to reflect on their health and treatment and gives them 'permission' to raise concerns with clinicians

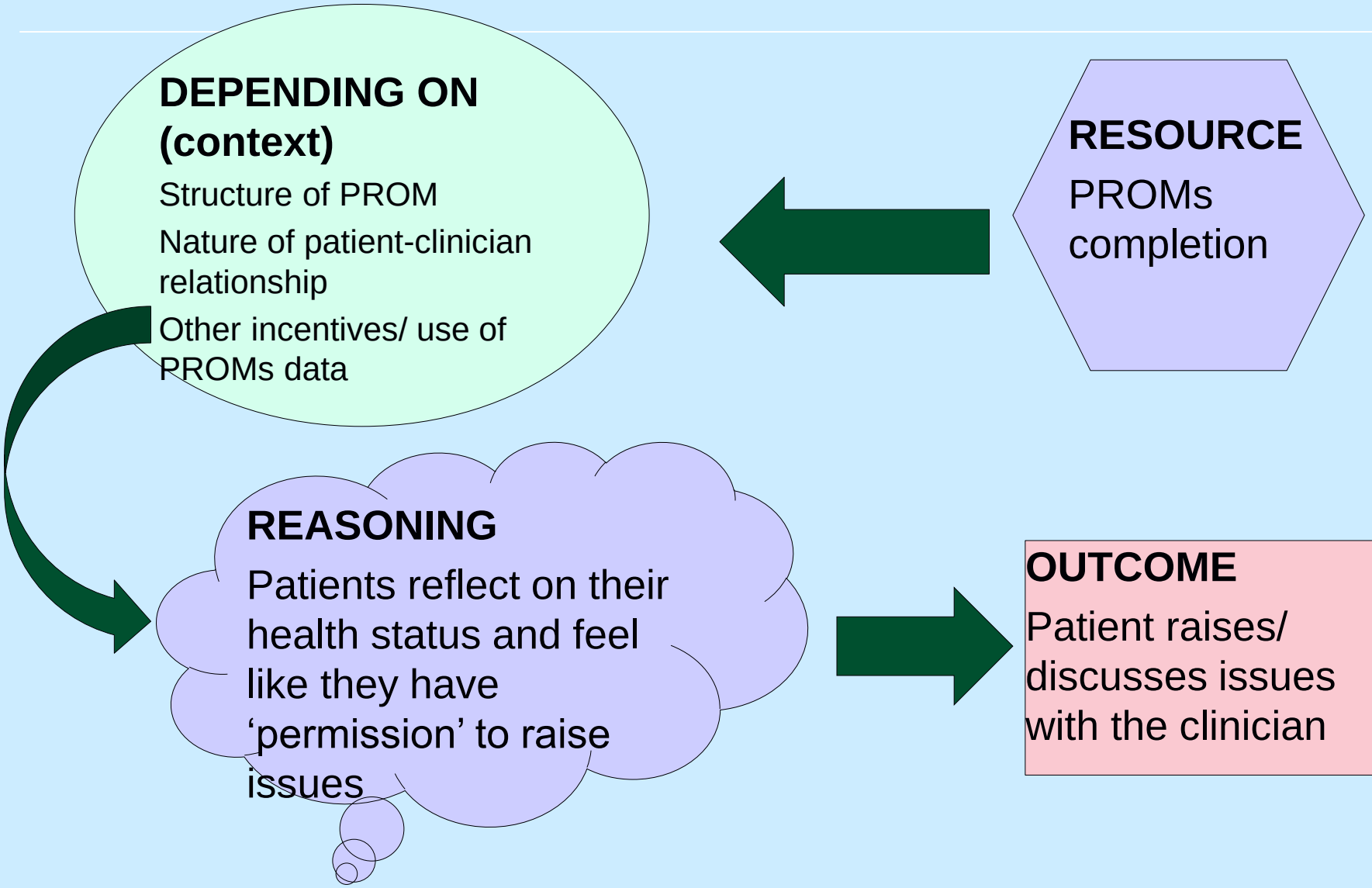
Context – the circumstances into which the PROM is implemented and how

We hypothesised the way PROMs worked and their impact would depend on:

- The structure of the PROM (eg – standardised vs individualised)
- The existing relationship between patients and clinicians
- Tensions arising from other uses of PROMs data (aggregate use, financial incentives)

Initial programme theory: PROMs act as a tool to support patients sharing/raising issues with clinicians

UNIVERSITY OF LEEDS



How did we test this theory?

UNIVERSITY OF LEEDS

Theory: Whether PROM completion support patients to reflect on their health and raise issues within the consultation depends on the structure of the PROM, the existing nature of the clinician-patient relationship and other, potentially conflicting uses of these data

Examined different contextual configurations by looking at PROMs use in different settings and using different PROMs:

		Contextual configuration each setting represents		
Setting	N studies	Nature of relationship	Structure of PROM	Use of incentives/ other use of data
Mental health primary care	4	Usually have existing relationship	Standardised	QOF, indicator of service quality
Secondary mental health care	6	New but can also be ongoing	Standardised	Indicator of service quality
Palliative care	13	New	Standardised and individualised	None

PROMs completion prompts self reflection

UNIVERSITY OF LEEDS

- Support for theory that **PROMs completion prompted patients to engage in self-reflection** – helped identify what was important and reflect on their health

"I think that [completing the questionnaire] helped me in my head as well … Well I started to think, you know about why I was getting depressed and that" (patient, primary care Dowrick et al, 2009)

- Also **signalled someone was interested in their feelings**

"*It makes you think constructively about how you are feeling, and I find putting it into words comforting, just knowing there is someone who is going to read it, and in some cases has the answers" (*patient, palliative care, Slater et al, 2004)

- For palliative care/terminally ill patients – could be emotionally difficult & if PROMs not fed back to clinicians, had a negative impact on HRQoL (Mills et al, 2009)

Context of PROM use: existing relationships

UNIVERSITY OF LEEDS

Patients and clinicians felt patients sharing concerns depended on a trusting relationship:

"*I think you'd have to have a trust thing built up first to actually share something with that person*" (young mental health service user, Stasiak et al (2012)

"*a lot of picking up depression is about rapport and about patients feeling comfortable and establishing a relationship*" (GP, Leydon et al, 2011)

Clinicians gained a lot of information from the WAY patients verbalised their concerns, that wasn't always evidence from PROMs scores

"*their story and their words tell me what they understand but also what words they use and whether there's any anger there or um.. denial*'" (palliative care nurse, Gamlen and Arber, 2013, palliative care)

"*you can't beat someone you feel confidence in and you feel comfortable with and all these things come out and no amount of bits of paper is going to change that*" (palliative care patient, Slater and Freeman, 2004)

How context shapes clinical use: Structure of the PROM:

UNIVERSITY OF LEEDS

Clinicians in primary and secondary mental health settings perceived standardised PROMs could constrain the relationship/trust building process:

"*If you've had a very loaded consultation…the HAD scale can appear to trivialise the depth of emotions*" (GP, Leydon et al, 2011)

"*I like to let them verbalise their concerns rather than handing them a bit of paper and say 'tick boxes*'" (palliative care nurse, Gamlen and Arber, 2013, palliative care)

They found it hard to fit the PROM into the flow of the consultation:

"*Where do you plonk those great big… bombshells in the middle of a normal consultation with somebody*" (GP, Leydon et al, 2011)

"*they.. break down in tears and tell you how depressed they're feeling…. and then 'oh now I've got this questionnaire to fill out' I just think its so inappropriate sometimes*" (GP, Mitchell et al, 2011)

How context shaped clinical use of PROMs

UNIVERSITY OF LEEDS

Clinicians developed strategies to use standardised PROMs in a way that enabled them to maintain the clinician –patient relationship

- Avoided using them altogether
- Used them at the end of the consultation or in later meetings when they had built up a relationship with the patient
- Adapted how they were used (changed items, omitted items, altered how they were administered) – may have affected their validity
- Used them in a ‘relational way’ – sitting by the patient as they completed the PROM to understand and explore how and why they arrived at their answers (eg, Krawczyk & Sawatzky, 2018)

Individualised PROMs

UNIVERSITY OF LEEDS

Clinicians in palliative care and secondary mental health services perceived **individualised** PROMs supported the relationship building process

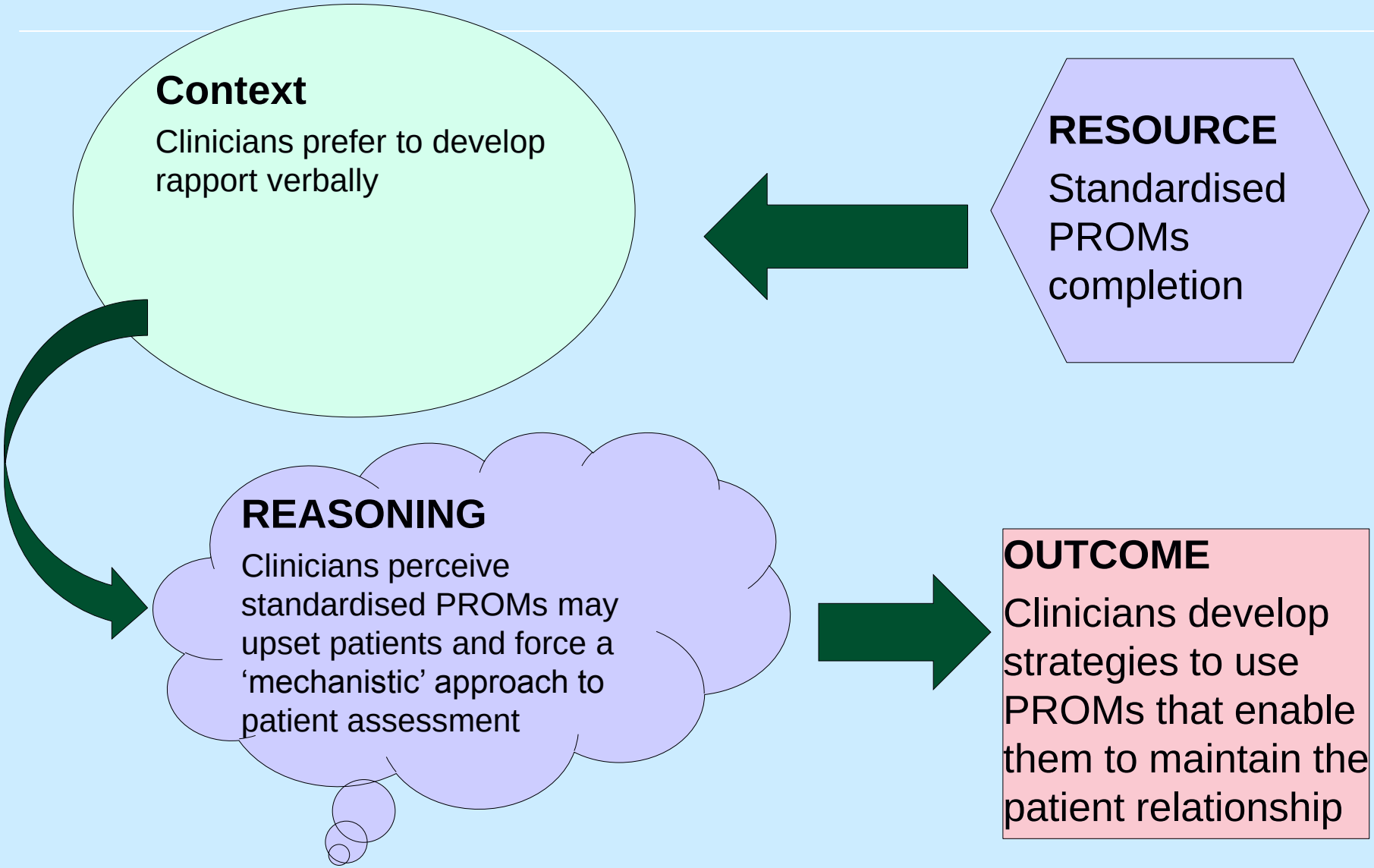
Therapists felt completion of the SEIQoL helped them to "*form a better relationship and trust with the service user*" because it enabled them to "*get alongside the service user more quickly*" (counsellor, drug and alcohol services, Cheyne et al, 2001)

"*I feel that the tool really helps the client to tell their story*" (palliative care, Annells and Koch (2001)

- Individualised measures acted as a 'conversation opener'
- However, less useful as an outcome measure

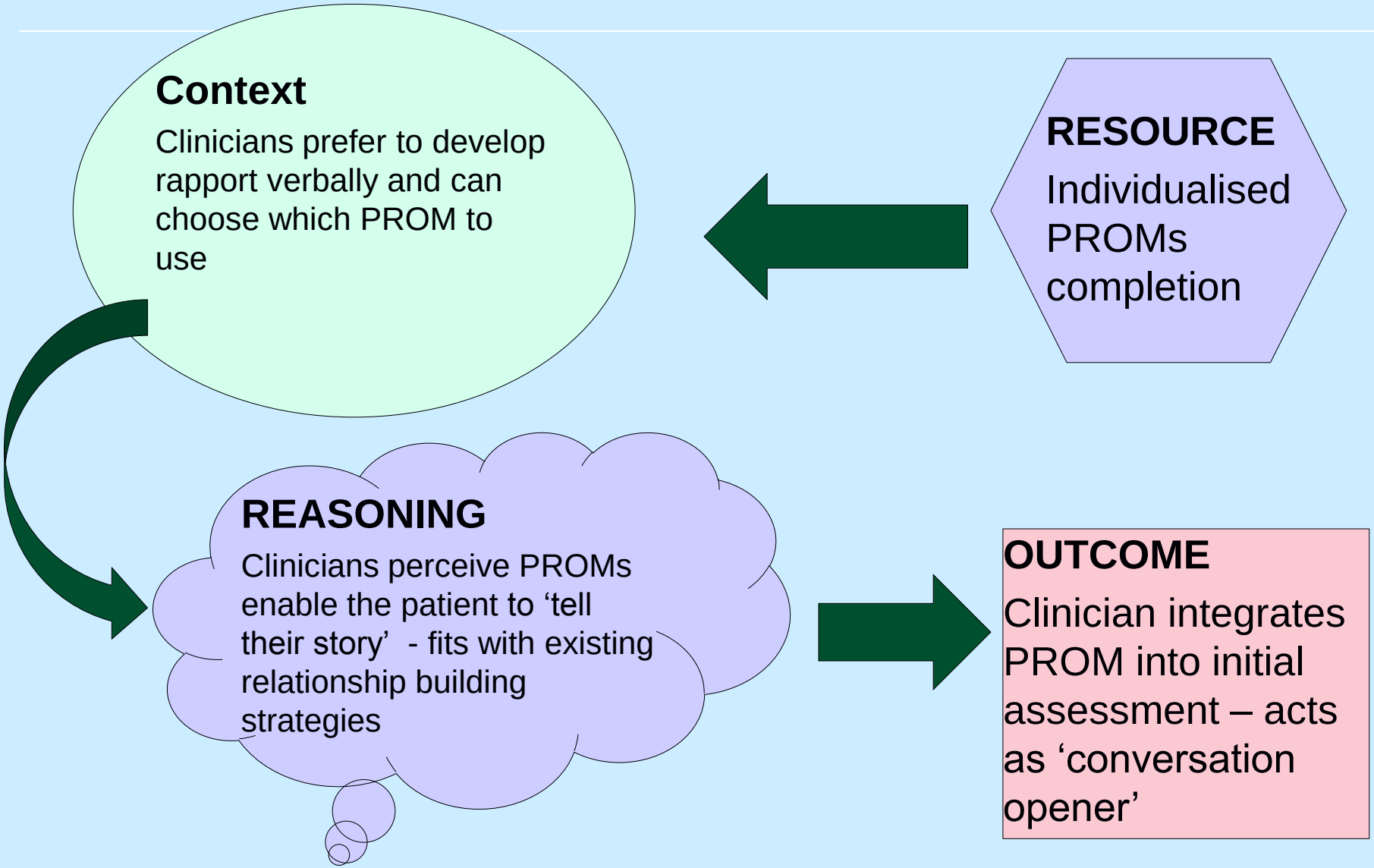
PROMs act as a tool to support patients sharing/raising issues with clinicians

UNIVERSITY OF LEEDS



PROMs act as a tool to support patients sharing/raising issues with clinicians

UNIVERSITY OF LEEDS



Conclusions

UNIVERSITY OF LEEDS

- PROMs completion can enable patients to reflect on their situation, makes them feel someone is interested in them and give them ‘permission’ to raise issues

- We need to pay more attention to the process and impact of PROMs completion on patients – not a ‘neutral’ act of information gathering

- Also need to think about how PROMs completion and feedback influences not just the ‘information exchange’ and ‘decision making’ functions of clinician-patient interactions, but also the ‘**relationship building function**’

- Clinicians use of standardised PROMs could constrain the ways in which they usually communicated with patients while individualised better reflected this process

- PROMs use is shaped by and affects the clinician patient-relationship; Clinicians adapted how they used PROMs to render them compatible with the ongoing work of managing relationships

Further information

UNIVERSITY OF LEEDS

Greenhalgh J, Gooding K, Gibbons E, Dalkin S, Wright J, Valderas JM, Black N (2018) How do patient reported outcomes measures (PROMs) support clinician-patient communication and patient care? A realist synthesis, *Journal of Patient Reported Outcomes*, 2:42: https://doi.org/10.1186/s41687-018-0061-6

Greenhalgh J, Dalkin S, Gibbons E, Wright J, Meads D, Valderas JM and Black N (2017) How do patient reported outcome measures (PROMs) data stimulate health care improvement? A realist synthesis, *Journal of Health Services Research and Policy*, https://doi.org/10.1177/1355819617740925

Greenhalgh J, Dalkin S, Gooding K, Gibbons E, Wright J, Meads D, Black N, Valderas JM and Pawson R (2017) Functionality and feedback: a realist synthesis of the collation, interpretation and utilisation of patient-reported outcome measures data to improve patient care, *NIHR Journals Library*, 5(2).

Greenhalgh J, Pawson R, Wright J, Black N, Valderas JM, Meads D, Gibbons E, Wood L, Wood C, Mills C, Dalkin S (2014) Functionality and feedback: a protocol for a realist synthesis of the collation, interpretation and utilisation of PROMs data to improve patient care. *BMJ Open* 2014;4:e005601.doi:10.1136/bmjopen-2014-005601