Can primary care nurses improve integrated care and self-management for long-term conditions –the person centred assessment method. 2015-2016

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Nursing, Midwifery and Allied Health Professions Research Unit

Improving health through research CHIEF SCIENTIST OFFICE

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PCAM

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NHS National Institute for Health Research

Today

- What's the problem?
- What's PCAM?
- Describe the feasibility/pilot trial
- Did nurses using PCAM do what we anticipated/hoped?
- Was PCAM acceptable for nurses and patients?
- Lessons learned

What's the problem?

Long Term Conditions

- COPD - chronic obstructive pulmonary disease
- DM – diabetes mellitus – types 1 and 2
- CHD – coronary heart disease

Health & Social Care

- Scotland's 20/20 vision (2011)
- Integration of Health & Social Care

  Public Bodies (Joint Working) (Scotland) Bill (Scottish Parliament 2014)

What's the problem?

Long term conditions are an increasing burden to individuals and to society.

- **42%** of the Scottish population lives with one or more LTC (Barnett 2012).

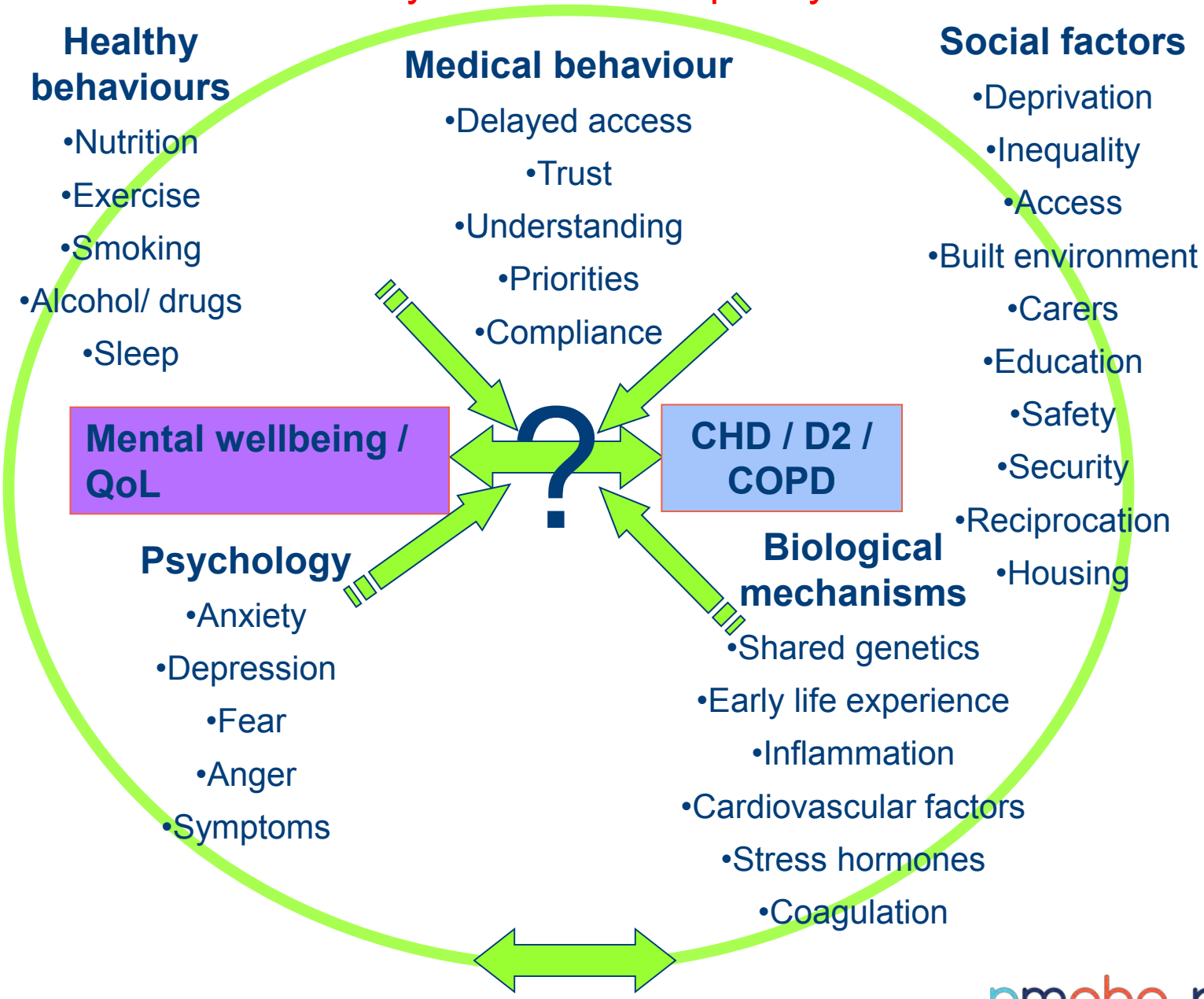
- costs to NHS Scotland will reach **£2.15 billion** by 2025 (Bunt 2010).

What's the problem?

Supporting self-management is a key to the management of long-term conditions (LTCs) in the UK.

- the association between chronic disease and socioeconomic deprivation has been well documented (Barnett 2012, Marmot 2010).

BioPsychoSocial Complexity



Why is biopsychosocial complexity important for LTC care?

1. Risk factors for increased morbidity and secondary conditions

2. Psychosocial problems interfere with post diagnosis treatment and self-management

3. The opportunity to address social inequalities in mental wellbeing

It's so complex
When can we intervene?

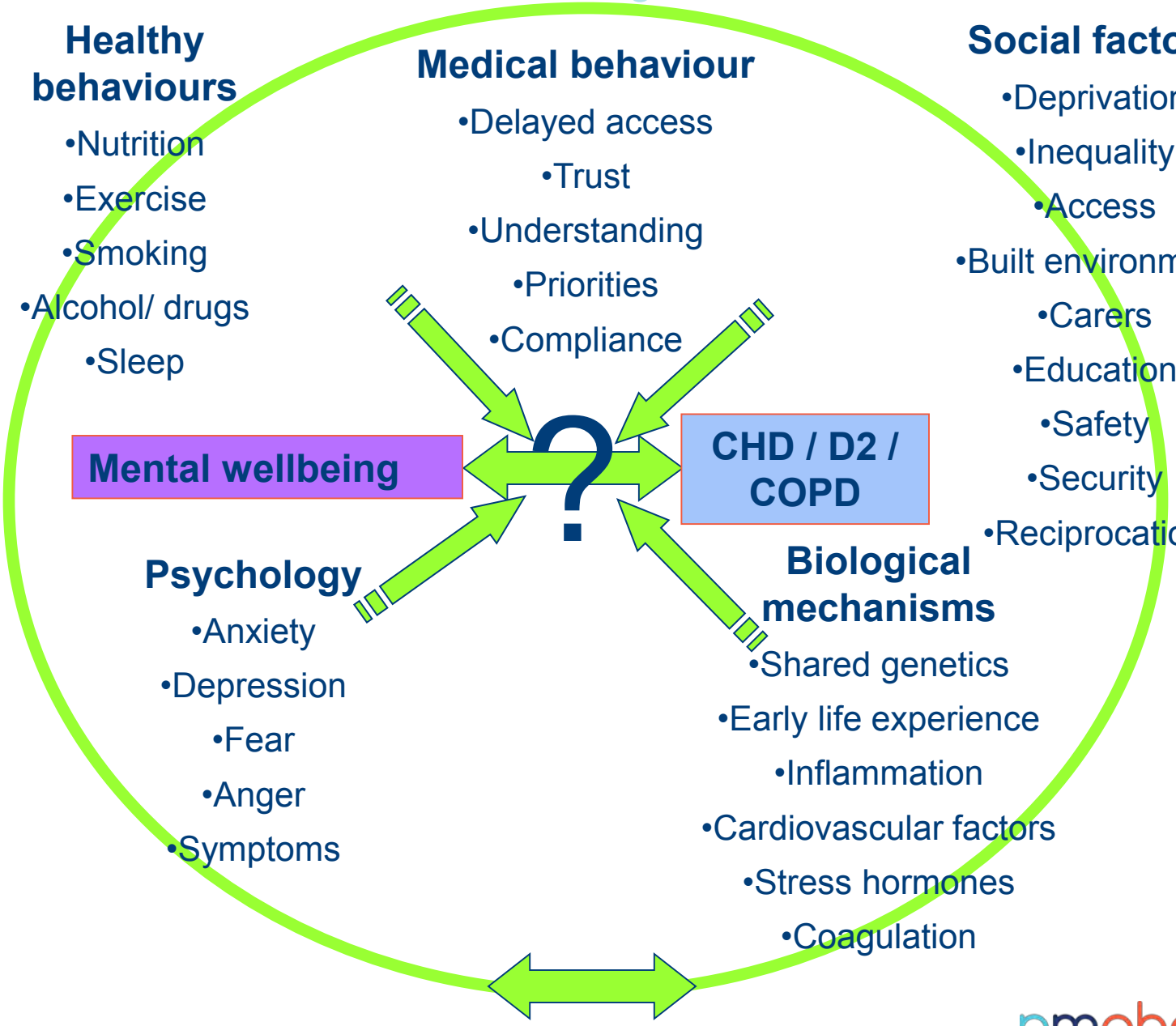
Opportunity - Annual reviews - Scotland

- Diabetes – some 12 or 13 monthly, some 6 monthly.
- “SIGN…….states that everyone with diabetes receives nine care processes every year to monitor the effectiveness of diabetes treatment,” (State of the Nation 2015)

But Reviews are Busy

- With so much to do, the review risks becoming transactional rather than relational.
- A checklist rather than a discussion.
- Nurses feel they need to manage “patient agenda” vs nurse agenda.
- Time and training for psychosocial assessment is limited

How could mental wellbeing be related to LTCs?



Frustration

Nurses and GPs often report frustration that year after year patients don't learn the lessons and make the changes needed.

- Some say they don't have the resources to take a supportive health psychology strategy

  & the problems are often beyond their influence
- Some view it as solely a patient level problem.

What's PCAM?

PATIENT-CENTERED CARE?

How was PCAM Developed?

- INTERMED – chronic pain, diabetes
- MCAM – USA, diabetes, primary care, MDT
- MECAM – Keep Well, Scotland – adapted for anticipatory care – developed and used by nurses in socio-economically deprived populations. Adapted version being used in 1 Health Board.
- PCAM – Adapted for LTCs. Co-created by researchers, healthcare and patients.

PCAM aims to:

- provide a more whole person, bio-psychosocial, naturalistic assessment
- unravel the biopsychosocial complexity
- facilitate person centred care in a meaningful way

Clinical ID: _ _ _ _ _ _ _ _

Remove before transfer to study team

Patient Centred Assessment Method ID: 2_ _ _ _ Date: _ _ / _ _ / 2015

PCAM vs 1-2

Instructions: Use this assessment as a guide, ask questions in your own words during the consultation to help you answer each question. Circle one option in each section to reflect the left of complexity relating to this client. To be completed either during or after the consultation.

Health and Well-being

1. Thinking about your patient's physical health needs, are there any symptoms or problems (risk indicators) you are unsure about that require further investigation?

No identified areas of uncertainty or problems already being investigated	Mild, vague physical symptoms or problems; but do not impact on daily life or are not of concern to client	Moderate to severe symptoms or problems that impact on daily life	Severe symptoms or problems that cause significant impact on daily life

2. Are your patient's physical health problems impacting on their mental well-being?

No identified areas of concern	Mild impact on mental well-being e.g. "feeling fed-up", "reduced enjoyment"	Moderate to severe impact upon mental well-being and preventing enjoyment of usual activities	Severe impact upon mental well-being and preventing engagement with usual activities

3. Are there any problems with your patient's lifestyle behaviours (smoking, alcohol, drugs, diet, exercise) that are impacting on physical or mental well-being?

No identified areas of concern	Some mild concern of potential negative impact on well-being	Moderate to severe impact on client's well-being, preventing enjoyment of usual activities	Severe impact on client's well-being with additional potential impact on others

4. Do you have any other concerns about your patient's mental well-being? How would you rate the severity or impact on the patient?

No identified areas of concern	Mild problems – don't interfere with usual activities	Moderate to severe problems that interfere with usual activities	Severe problems impairing most daily activities

Social environment

1. How would you rate their home environment in terms of safety and stability? (including domestic violence, insecure tenancy, neighbour harassment)

Consistently safe, supportive, stable. No identified problems	Safe, stable, but with some inconsistency	Safety / stability questionable	Unsafe and unstable

2. How do daily activities impact on the patient's well-being? (include current or anticipated employment, work or caring responsibilities)

No identified problems or perceived positive benefits	Some general dissatisfaction but no concern	Contributes to low mood or stress at times	Severe impact on poor mental well-being

3. How strong would you consider their social network to be? (family, friends, work)

Good participation with social networks	Adequate participation with social networks	Restricted participation with some degree of social isolation	Little participation, lonely and socially isolated

4. How stable do you consider their financial resources? (include ability to afford all required care and medical costs or ability to live well)

Financially secure, resources adequate. No, identified problems	Financially secure, some resource challenges	Financially insecure, some resource challenges	Financially insecure, very few resources, immediate challenges

Health literacy and communication (ability to find, understand and use information to live well)

1. How well does the patient now understand their health and well-being (symptoms, signs or risk factors) and what they need to do to manage their health or access support?

Reasonable to good understanding and already engages in managing health or is willing to undertake better management	Reasonable to good understanding but do not feel able to engage with advice at this time	Little understanding which impacts on their ability to undertake better management	Poor understanding with significant impact on ability to manage health

2. How well do you think your patient can engage in healthcare discussions (barriers include language, deafness, aphasia, alcohol or drug problems, learning difficulties, concentration, health beliefs, lack of understanding)?

Clear and open communication, no identified barriers	Adequate communication, with or without minor barriers	Some difficulties in communication, with or without moderate barriers	Serious difficulties in communication, with severe barriers

Support for Client

1. Do other services / support need to be involved to help this patient?

Other care / services not required at this time	Other care / services in place and adequate	Other care / services in place, but not sufficient	Other care / services not in place and required

2. Are services / support involved with this patient well coordinated?

All required care / services in place and well coordinated	Required care / services in place and adequately coordinated	Required care / services in place with some coordination barriers	Required care / services missing and / or fragmented

Routine care	Active monitoring	Plan action	Act now
What action is required?	Who needs to be involved?	Barriers to action?	What action will be taken?

Notes:

PCAM aims to provide a more whole person, bio-psychosocial, naturalistic assessment.

- 5 Domains
  - Health and wellbeing
  - Social environment
  - Health literacy and communication
  - Support for client
  - Actions – referrals and signposting
- Traffic light of need for support rather than scoring

- A system, not a scale
  - Nurse skills and training are core
  - Naturalistic interview conducted throughout the review
  - Nurse completed form, guiding and recording...
    - A mini – reference card can be used during the consultation – to prevent interference with consultation.
  - Identifies risk or need
  - Action plan, patient centred, identifying barriers
  - Resource pack (a locally tailored, low tech' list of local and national resources for referral / sign-posting)

It is anticipated that PCAM will:

- ❑ Open-up psychosocial discussion and
- ❑ Normalise person centred, holistic discussion
- ❑ Help to document that discussion
- ❑ Lead to more non-medical services / self-help; including social referrals
- ❑ Improve an understanding of the relationship between mental wellbeing, mental health and physical health
- ❑ Enhance self-management

How did we deliver training?

- We adapted training in response to experience
- All training was in nurses' practice

- 2 1/2 hours presentation and discussion biopsychosocial complexity
  - Use of nurses own anon. cases
- 1 1/2 hours reflection
- 1 1/2 hours how to deliver PCAM with role play.
- *In your own words*
- ≥ 10 practice with 10 patients
- Review and open-access support

Feasibility/pilot Trial

PCAM is a Complex intervention

"Some dimensions of complexity

- Number of, and interactions between, components within the experimental and control interventions
- Number and difficulty of behaviours required by those delivering or receiving the intervention
- Number of groups or organisational levels targeted by the intervention
- Number and variability of outcomes
- Degree of flexibility or tailoring of the intervention permitted"

Craig et al, 2008

Cluster randomised feasibility/pilot controlled trial with embedded process and context evaluation

- **Is it feasible and acceptable to use the PCAM in primary care nurse-led annual reviews for those with LTCs?**

- Is it feasible and acceptable to run a cluster randomised trial of the PCAM intervention in primary care?

Craig et al, 2008

Cluster randomised feasibility/pilot controlled trial with embedded **process and context** evaluation

	Question	Method
Effectiveness	Does PCAM improve outcomes? Power calculation.	RCT
RCT Feasibility	Can the RCT be delivered in a range of teams? What adaptations are needed?	RCT Observations Interviews ADePT
PCAM Feasibility	Can PCAM be delivered in a range of teams? What adaptations are needed?	Observations Interviews ADePT
Process Evaluation	What was being tested? How was PCAM delivered?	Review audio-recordings Observations Interviews
Context evaluation	What issues affect implementation and efficacy?	Observations Interviews Normalisation Process Theory

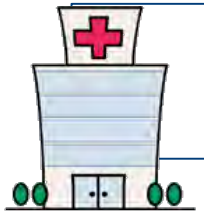
Challenges running primary care studies in Scotland

- Practices taken under HB control
- Short staffed
- Getting sickness cover is difficult
- Asked to do more and more
- GPs and nurses nearing retirement

So, we are not proposing here to go into a full RCT

Before the RCT, we ran patient and staff focus groups

Adapted training, processes and materials



Practices recruited to study
N=6 (4% eligible)
NHS FV 0 , NHS GGC 2 , NHS Grampian 4

Nurses recruited to study
N=8
NHS GGC 3 , NHS Grampian 5

Each nurse recruit ≥10 patients
Nurse completed form
Patient completed form.

Patient completed form 6-8 wks

Patient data anonymous to researchers, consent assumed by completion

Practices recruited to study
N=6 (4% eligible)
NHS FV 0 , NHS GGC 2 , NHS Grampian 4

1 practice planned drop-out

Nurses recruited to study
N=8
NHS GGC 3 , NHS Grampian 5

1 2

CAU
N=2
NHS GGC 1, NHS Grampian 1.

PCAM
N=3
NHS GGC 1, NHS Grampian 2.

PCAM Training & Practice

Each nurse recruit ≥10 patients
Nurse completed form
Patient completed form.

Patient completed form 6-8 wks

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CAU
N=2
NHS GGC 1, NHS Grampian 1.

PCAM
N=3
NHS GGC 1, NHS Grampian 2.

PCAM Training & Practice

≥10 patients
Forms

form 6-8 wks

≥10 patients
PCAM & forms

form 6-8 wks

190 patients with 111 followed-up

Practices recruited to study
N=6 (4% eligible)
NHS FV 0 , NHS GGC 2 , NHS Grampian 4

Nurses recruited to study
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CAU
N=2
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N=3
NHS GGC 1, NHS Grampian 2.

Audio-recording

PCAM Training & Practice

≥10 patients
Forms

form 6-8 wks

≥10 patients
PCAM & forms

form 6-8 wks

Audio-recording

Nurse & Patient Interviews

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Cluster randomised feasibility/pilot controlled trial with embedded **process and context** evaluation

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Process evaluation

- What are we actually testing?
- There will be variation in delivery between consultations, nurses, sites and over time.
- What is essential to improved outcomes and what can be adapted locally?

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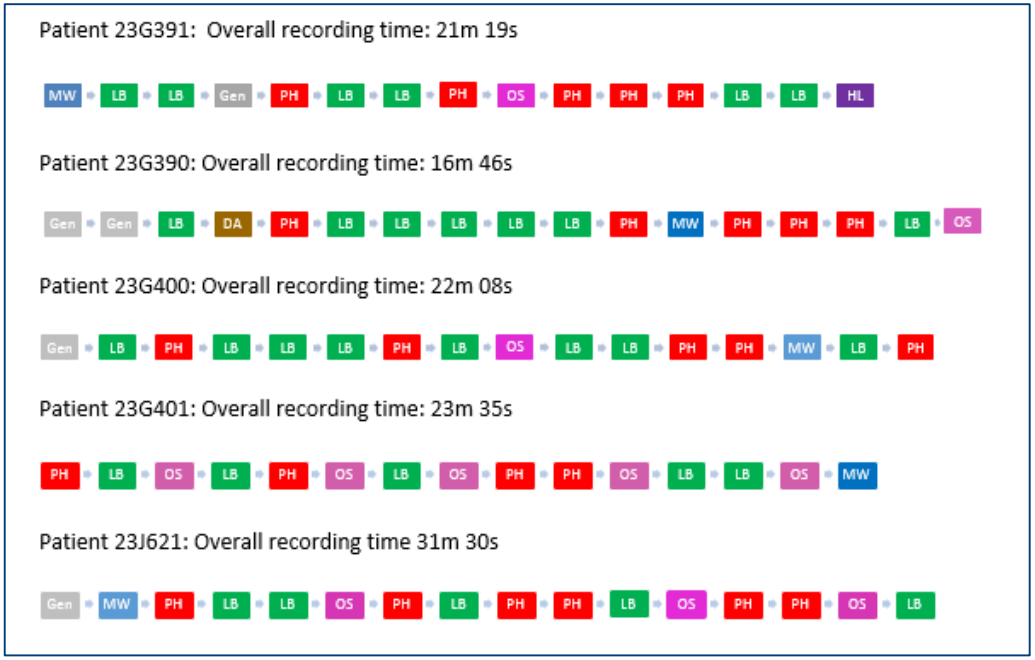
Testing what's being delivered

- Anon. Audio recordings, reviews before and reviews after PCAM implementation.
- Are the PCAM items discussed during the review? If so, does it have fidelity to the PCAM model?
- Can lessons be learned for nurse training and support?

Potential issues audio-recording

- Acceptability to nurses and patients
  - 4/6 nurses consented
  - All patients asked agreed
- Mechanics of remembering to start and stop the recorder

Pre



Gen (General)
PH (Physical Health)
MW (Mental Wellbeing)
LB (Lifestyle Behaviour)
HE (Home Environment)
DA (Daily Activities)
SN (Social Network)
HL (Health Literacy)
OS (Other Services)

Post

CAU

23J621

PN: '...you're generally keeping quite well yeah?'

Patient: 'Bit stressed.'

PN: 'And it'd be quite fine if we'd treatment for that wouldn't it!'

Patient: 'Mh mmm.'

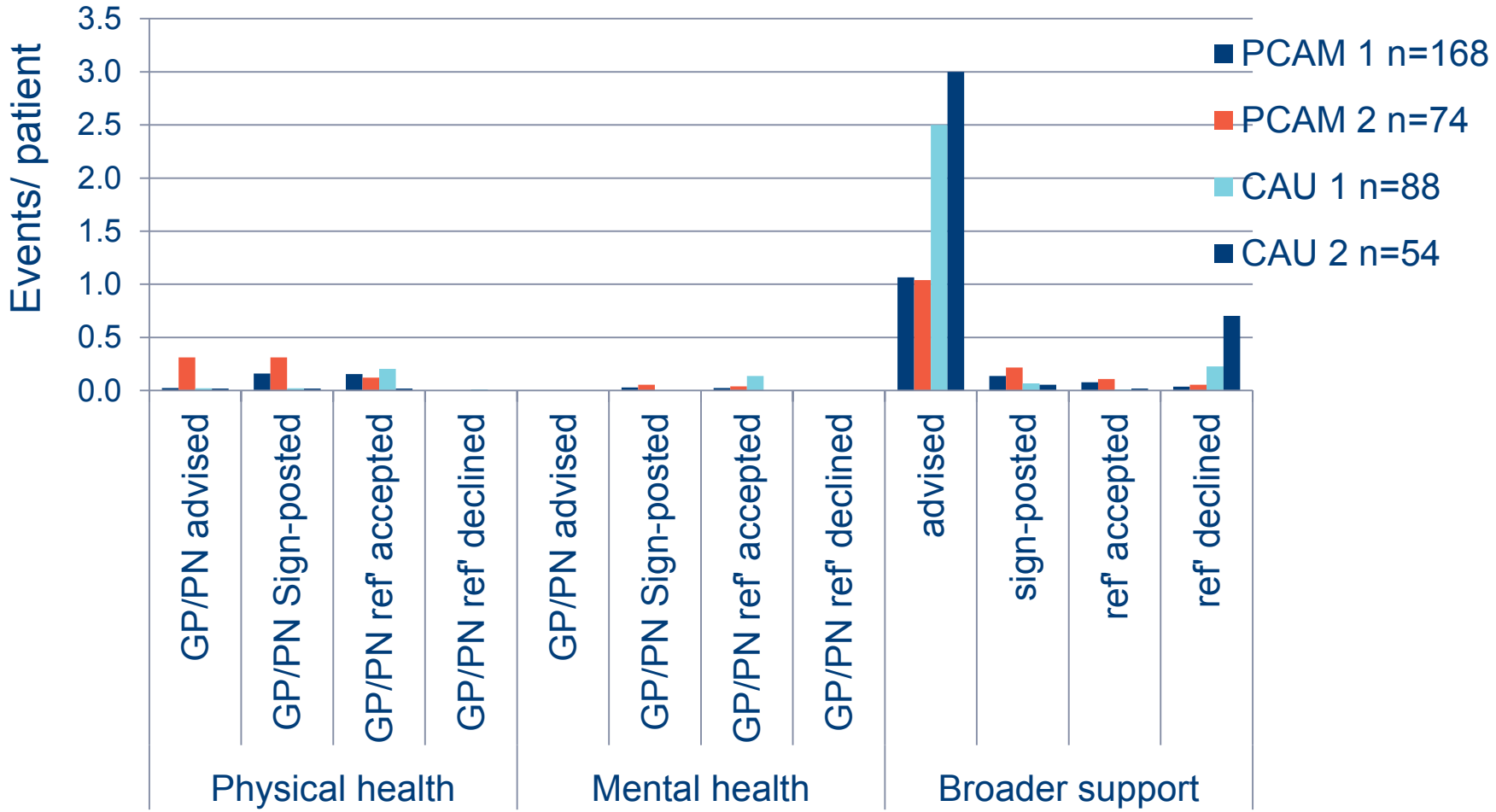
PN: So, breathing-wise, chest-wise, any issues, any coughs at all?'

PCAM

23G561

'And how are you feeling in yourself with all of this going on, I mean emotionally?' …….'Does your mood ever dip or d'you ever feel that you're struggling emotionally with what's been going on?'.

Advice, Sign-post, Referrals Before and After Randomisation



Length of consultation (Mins)

Phase	Group	N	Min	Max	Median
1	PCAM	62	15	40	30
	CAU	40	12	40	25
2	PCAM	43	10	65	35
	CAU	33	15	40	25

Phase	Group	Mann-Whitney U	Z	P (2 tailed)
1	PCAM vs CAU	1001	-1.677	0.094
2	PCAM vs CAU	362.5	-3.706	0.000

Patient Experience of PCAM

Consented N=6/40
Only PCAM post-randomisation

Patients blinded to allocation
Asked

- Experience of condition
- Experience of the review and any R/Sp
- Opinions about biopsychosocial influences
- Opinions about nurses asking psychosocial

- Most were happy with their care before
- Not all overtly noticed a difference

But

- They described it as being conversational in style
- Some experienced deeper conversation about mood and health behaviours
- There was benefit just talking with someone
- All thought nurses should be asking about psychosocial issues
- Where they had concerns about it, it was around the possible burden on nurses

Yeah it's more as a chat than, you know, sort of ticking a box, you know, she more sort of generally just chats and tries to get you to communicate. (Patient Interview, Participant 23G438)

And I do remember that the time before I was quite upset because it was... it was just about a year to when my husband died and things were just making me upset. So we talked quite a bit in June about how I was feeling compared to the time before and she listened quite a lot to me and asked if she could do anything more for me because she thought maybe if I went to see a dietician, but I couldn't fit a dietician into my life just now [laugh]! So she was trying hard to try and help with the problems that she thought I was having. (Patient Interview, Participant 23G411)

I think she could basically ask anything she wants if she thinks it's relevant and it may have an effect on people, it must have an effect on people.

(Patient Interview, Participant 23G438)

Nurse Experience of PCAM

N=6 (PN, PM)

Only PCAM post-randomisation

Asked

- Experience of training
- Experience of PCAM review
- Experience of Resource pack
- Facilitators/barriers to continued use

Training

- Too much science, but it was useful
- Valued the training
- Using their own cases was useful
- Particularly valued experiential / role play

PCAM Review

- Changing practice initially was difficult but nurses quickly became more familiar and comfortable with PCAM
- Nurses were surprised at how it deepened conversation
- They felt it improved relationships and their understanding of patients
- Some had got positive feedback of impacts on patient's lives

- Some felt it would be useful to integrate it into their clinical IT system

PCAM Resource Pack

- They reported using this frequently
- They had shared the pack with colleagues in the practice and outwith
- They liked the low tech' aspect

- There are sustainability issues, one PM had taken update responsibility.

Now, yes, now. I'm not saying... at the beginning you were still sort of stuttering your way through it, you know, you were sort of finding your feet, you know, but now you keep all the sort... when they're coming in for the review obviously you're talking about health and wellbeing anyway, you know, but in the cases of maybe social environment and things like that, you know, it's something you would never have brought up before but now when someone mentions 'oh my father's...' 'oh, so what like is it at home?' you know, your window's there then, you know. (Nurse Interview, Participant 21E042)

Intention to continue use

- All said they would continue to use PCAM

We don't only use it in CHD, diabetes, COPD, we use it in everything from our asthma patients... we use it in every sort of... even our hypertensive patients we use it, you know, we're using it... well, me and my fellow nurse we're both incorporating it into our daily tasks if you get what I mean. (Nurse Interview, Participant 21E042)

ADePT analysis of PCAM

Process for Decision-making after Pilot and feasibility Trials (Bugge et al. 2013)

- Systematic identification of problems & potential solutions
- Improve transparency of decision making process
- Choice to go to explanatory / pragmatic trial?

ADePT Recommendations

CONTEXT

- Policy and the medical practice need to be supportive
- MDT involvement
- Be considerate of training fatigue
- Nurses need autonomy and confidence
- Co-ordinate with other related programmes

ADePT Recommendations

TRAINING

- Different starting points of understanding and culture
- Needs flexibility
- More experiential
- Needs to be longitudinal, allowing time for reflection & experience
- More work on health literacy and planning
- Boundaries
  - Nurse role
  - “Pyramid of Psychological Need”

ADePT Recommendations

Resource pack

- Needs a champion

ADePT Recommendations

DOING PCAM

- Needs to be supported
- Integrate into PMS

THANK YOUs

All staff and patients
Scottish Primary Care Research Network

Our PPI Representatives

Trial Steering Committee – Chair Prof. Brian McKinstry, University of Edinburgh

NIHR HS&DR

The MECAM team, University of Minnesota, USA

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