Scaling up without leaving behind
- A perspective from the shop floor

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• Background
• Using programme in clinical setting
• Benefits
• Functional issues
• Barriers
• Potential for improvement
• Self-reflection
Intervention stems from commitment to integrate Mind and Body health

• Almost half patients with long term mental illness have at 1+ long-term physical health condition
• 30% people with long-term physical health conditions also have a mental health illness
• 15-20 years shorter life expectancy for people with severe mental illness or learning disability
• £8bn NHS spend p/a treating effect of poor mental health on physical illness

Part of a broad programme

• Informatics system enabling routine collection of patient-reported outcomes providing real-time feedback to inform clinical care
• Development of care pathways for those patients identified via above system
• Mental health training for physical health care professionals
• MOOC (Massive online learning course) for healthcare professionals and patients with long-term conditions
• Seminar series
• Pseudonymised database to facilitate further research
Intervention

• Multi-site across three acute hospital trusts
• 50+ adult outpatient clinics long term-illness (Diabetes 1)
• 50k + patient interactions (2017)
• Patient questionnaire (voluntary) asks patients about their long-term condition
• Patient-reported outcomes on depression, anxiety, QoL
• Informed consultation
• Referral pathways where necessary
Digital Questionnaire - Voluntary Consent
Depression - 9 item patient health questionnaire (PHQ9)
Anxiety – 7 item generalised anxiety (GAD7)
Questions specific to diabetes 1
Smoking

Patient

Receptionist/HCP/Facilitator

Doesn’t complete

Lost

Completes feasibility questions (reasons for not completing questionnaire)

Not enough time/ipads/Wifi problems
Insufficient English
Learning Difficulties
Declined to/Other – Why?
Lost ?

Completes Consultation (Consultant or Nurse)

Liaison psychiatry
Clinical psychologist
Notify GP – suggest IAPT
No action needed
Benefits

General

- Grounded in multi-disciplinary data-rich research
- Real time patient information enables better tailored care
- Embedded in regular clinical practice
- Provides clinicians with tools/prompts to enable joined-up care - particularly important for those with less confidence/experience/training in Mind/Body
- Replicable and with great potential for scale up

Personal

- Build up rapport with patients
- Answer patient queries/concerns
- Intervention champion
- Help patients to complete questionnaire (when requested by them)
- Provide feedback to clinicians
- Great staff buy-in and support
Positive Informal Patient Feedback

‘I never realised how much my diabetes was affecting my mood until I did this questionnaire’

‘It’s helped me think about what I wanted to ask the doctor, it was like taking notes in’

‘I thought I’d just do it as I get really bored with all the waiting but I realise it actually helps me’

‘There’s no way I’d talk to anybody about my mental health but now I’m not so embarrassed.

‘I really like my consultant but this helps me trust (them) more’
Problems with completing (functional and emotional)

- Despite consent/GDPR statement patients still wary
- Questionnaire design – comprehension and relevance. Some patients didn’t understand the diabetes-related questions. For others a question wasn’t relevant but no option to pass so discontinued - led to frustration and attrition.
- Fear of right and wrong answers given closed nature of questionnaire
- No function for patients to add ‘any other comments’ where relevant
- Fear of consequences of not completing (do no harm)
- After completion worried about how they were feeling (unintended consequence)
Reducing Functional Issues

• Update and reinforce GDPR statement
• Clear statement – choosing whether or not to complete will in no way affect your care
• Relook at questionnaire design. Consider revision by relevant HCP/patients/carers – testing
• ‘Any other comments’ difficult to absorb into some quantitative data but provides an avenue for patient feedback – useful for service evaluation and improvement.
Broader Barriers

Health interventions increasingly reliant on patient use of digital technology, particularly those seeking to operate at scale. Failure to acknowledge this means researchers, healthcare professionals and funders preach to the converted and already health-literate and risk continued exclusion for others

https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04

https://www.lloydsbank.com/banking-with-us/whats-happening/consumer-digital-index/key-findings.asp#DD
Barriers in context of intervention

- Certain groups unable to complete questionnaire included (but not exclusive to)
  - elderly, ethnic minorities, disabled, learning disabilities
- In role for 15 months and didn’t see any change
- Many wanted to engage with the intervention but frustrated that they couldn’t do so
- Some barriers potentially captured in the feasibility questionnaire (learning disabilities, insufficient English) but not all
- Digital exclusion not appreciated
Wanted to complete, but…

‘When I was diagnosed I started to die’

‘It’s all got too much for me’

‘I’d love to do it, but I don’t have the mental energy’

‘I’ve got enough on at the minute with my housing and benefits to bother with this, I’m about to give up’
Completion of questionnaire with patient

- Only when requested by patient
- Quiet area (although not completely private)
- Stressed confidentiality
- As with post-it notes any comments added verbatim
- Added post-note to say completion supported by me

Issues

- Not able to facilitate questionnaire other patients
- Ethics – was informally told I could do so
- Willingness/ability to do so due to previous training, not any offered by intervention
- Where patients shared distressing information I had no means of support
Next steps

• Reducing barriers must be an intervention priority
• Need to look at ways for capturing quantitative data on those that can’t use intervention
• Qualitative/PPI approach – formally identify patient groups, what do these patients see as the barriers? how can they be best supported?
• If individual support offered must be standardised, yet flexible
• Who can provide this support given resource pressures?
• Decide on who is best suited to facilitate questionnaire – clinic staff or facilitator?

If it is facilitators…
Training

• Model - SLaM Support and Recover Enablers (old-age)
• Recruited specific volunteer group (mainly trainee psychologists)
• Provided thorough training – general and specific to patient group
• Regular supervision (group and individual where requested)
• Volunteers highly valued and supported

Requires buy-in and set up resources but if volunteer group valued, embedded they can support clinical teams
Self Reflection

15 months volunteering – time to move on…

• Began screening out patients based on time constraints and previous experience (bias)
• Frustrations with lack of communication and two-way feedback
• Lonely
• Lack of training
• Felt under-utilised
• Began viewing time in clinic through prism of research rather than a service intervention so not staying true to supposed role