Asking about ACEs in health settings

Summarising learning from pilots in England and Wales

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Introduction

Today's seminar

- Introduce concept of ACE enquiry and summarise global research
- Outline current debates and challenges
- Describe pilot studies evaluated in England and Wales
- Implementation of ACE enquiry with health visitors in Anglesey
- Summarise evaluation findings
- Recommendations for future implementation, research and development
- Questions



Background



Routine enquiry

The principles

- Universal asking all, regardless of risk indicators
- Removing stigma
- Proactive services/practitioners care and want to understand
- Identifies those that might be at greater risk of certain poor outcomes holistic NOT deterministic
- Allows practitioners to tailor existing provisions support accordingly
- Hypothesised therapeutic benefit for ACEs (Felitti USA)
- NB. I may call it something different...



Starting the conversation

Studies of ACE enquiry

Child Abuse & Neglect 91 (2019) 131-146

FISEVIER

Contents lists available at ScienceDirect

Child Abuse & Neglect

journal homepage: www.elsevier.com/locate/chiabuneg

The evidence base for routine enquiry into adverse childhood experiences: A scoping review

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Adapted from: Ford, Hughes, Hardcastle et al, 2019



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Understanding the evidence

What do we know so far?

- Mainly small-scale studies exploring practitioner attitudes or current practice
- Only a very small number of known pilots of ACE enquiry (from the US)
- US studies provide tentative support for positive experiences of practitioners and service users
- But limited examination of impacts or outcomes
- Question mark as to transference of findings to UK state-supported health system



Key issues and challenges

The debate continues...

Enquiry is premature
Lack evidence of: the
potential harms/benefits
of enquiry;
& effective interventions
to support those identified
as having ACEs
(Finkelhor, 2018)

Cannot do nothing
ACEs a public health
crisis; not about
screening, but must
adopt emic approaches
to patient-centred health
care
(Dube, 2018)

Key issues and challenges

Practitioners' concerns...

This will just open a can of worms

We do that already

I have nowhere to refer people to

Etc...

People don't want to have to think about those types of things

> It would take up more time and we are already overstretched



The pilot initiatives





The development of an ACE enquiry model in England

Routine Enquiry into Adversity in Childhood (REACh)

- Developed and delivered by Lancashire Care NHS Foundation Trust
- Adapted and applied to GP setting for NHS England pathfinder study
- REACh aims to support practitioners in changing how they ask about patient history and build confidence to respond to ACE disclosure
- Model previously implemented in range of universal and targeted services, but this was the first independent evaluation of implementation





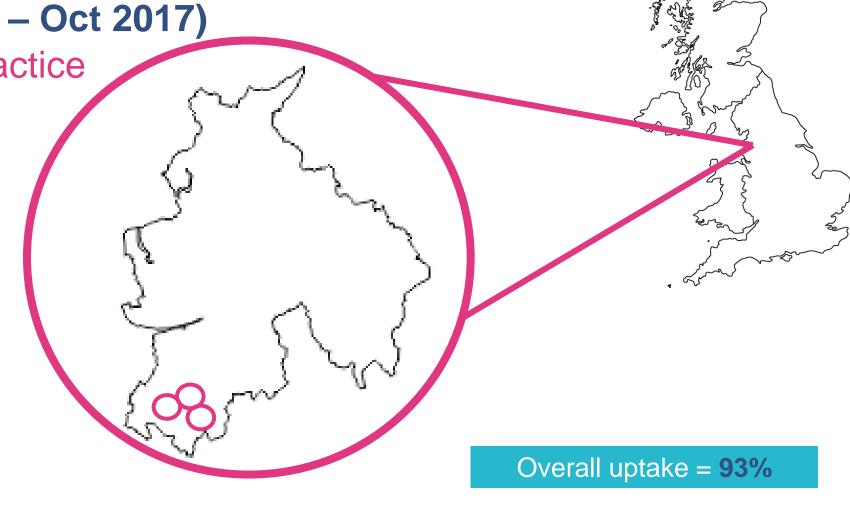
REACh Pilot (April – Oct 2017)

1 large multi-site practice

Practice A

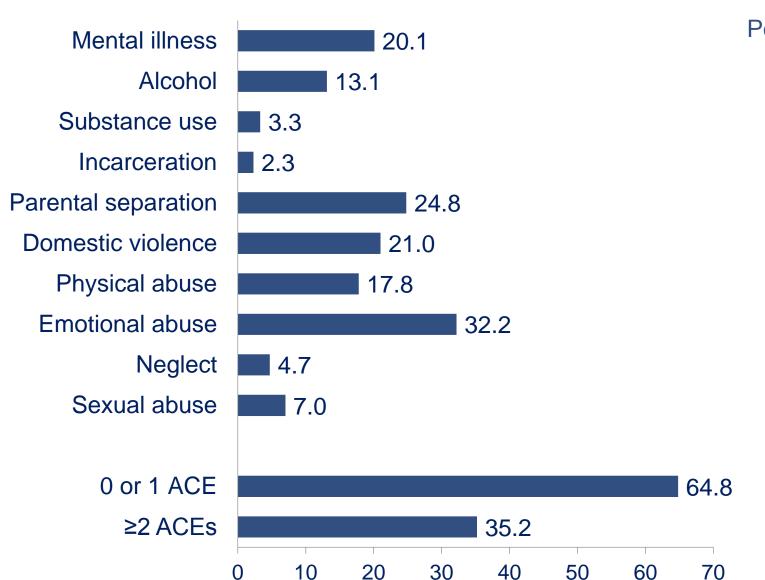
Practice size = 16,000 Enquiring clinicians = 3 GP; 2 ANP; 1 HCA Total enquiries = 218 Decliners* = 16

Mean age = 52.2 years
Gender = 65% female
Deprivation = 32% (high)
Chronic health = 31% with multiple
long term conditions; 17% current
smokers; 26% mental health



GP=General Practitioner; ANP= Advanced Nurse Practitioner; HCA = Healthcare Assistant *Number of decliners was recorded by reception at each site; reasons for decline not sought/given





People with 2 or more ACEs were...



more likely to have asthma



more likely to be living with multiple long term conditions



more likely to have experienced mental health problems



The ACE agenda in Wales

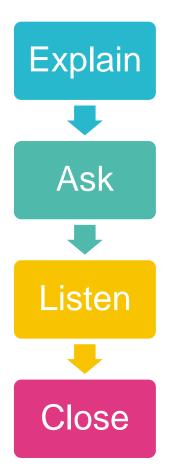




Introducing ACE enquiry in health settings



- Welsh Government, public services and voluntary sector on national agenda to prevent ACEs, build resilience and support those who have already suffered their effects
- Grounded in key policy and strategy
 - Health and Social Care Plan (A Healthier Wales)
 - Well-being of Future Generations
 - Healthy Child Wales Programme
- Models of ACE enquiry designed and delivered by the health board, with the support of a consultant trainer/facilitator





Overall uptake = 91%

GP Pilot (Nov 2017 – Apr 2018)

3 Practices

Practice D

Practice size = 5,500 Enquiring clinicians = 4 GP; 2 NP

Total enquiries = 168 Decliners* = 32

Practice C

Practice size = 7,000 Enquiring clinicians = 2 GP Total enquiries = 200 Decliners* = 8 Mean age = 53.4 years
Gender = 61% female
Deprivation = 10% most deprived

→ 50% least deprived
Chronic health = 28% with
multiple long term conditions;
23% current smokers; 33%
mental health

Practice B

Practice size = 10,000
Enquiring clinicians = 4 GP
Total enquiries = 203
Decliners* = 14

GP=General Practitioner; NP= Nurse Practitioner
*Number of decliners was recorded by reception at each site; reasons for decline not sought/given



Experiencing current mental health issues Referral to secondary care (previous year) 75% 53% 0-1 ACE 46% 42% 50% ≥2 ACEs 34% 39% 39% 31% 28% ^{23%} 19% 27% 25% 16% 8% 18-30yrs 31-50yrs 51-70yrs ≥71yrs 18-30yrs 31-50угѕ 51-70yrs ≥71yrs

Patient arrives at surgery

Reception team determine eligibility for ACE enquiry

Patient eligible: Provided with information sheet and ACE questionnaire to read and complete

Not eligible: No further action

Patient completes ACE questionnaire in waiting area prior to appointment

Patient declines participation

Patient takes completed questionnaire to appointment and hands to clinician



Clinician discusses presenting problem with patient and offers opportunity to discuss ACE questionnaire responses

Patient has no
 ACEs
 Patient discusses ACEs and impact on current health and wellbeing

Patient chooses not to discuss ACEs

Patient receives referral for additional support

Patient does not require further support at this time

Patient is reassured that they can request a follow up appointment to discuss ACEs at any time

Patient is provided with information sheet about local and national support services



Health Visitor Pilot (Oct 2017 – Jul 2018)

Whole service

ACE Group (6 weeks)

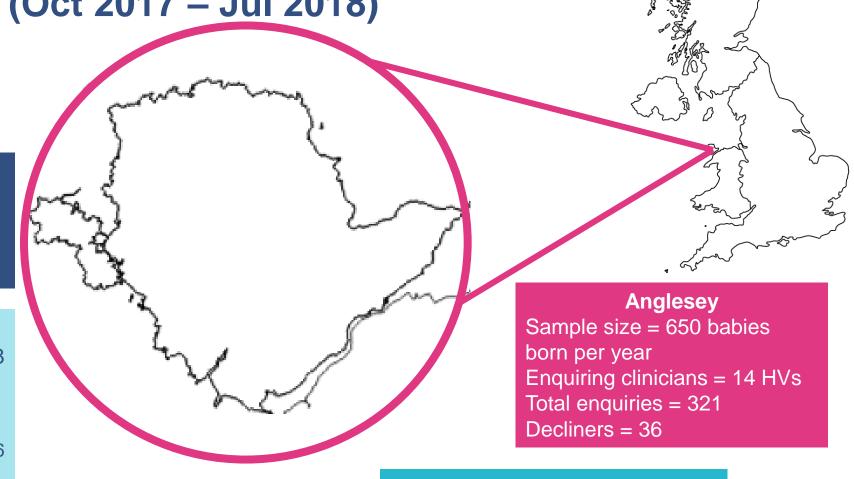
Agreed to take part = 174; Declined =13

NB. In a further 8 cases, the HV felt it was not appropriate to invite the mother to take part.

Comparison Group (6 months)

Agreed to take part = 147; Declined = 18

NB. In a further 10 cases, the HV felt it was not appropriate to invite the mother to take part; 3 mothers moved out of the area before 6 months.



Overall uptake = 90%

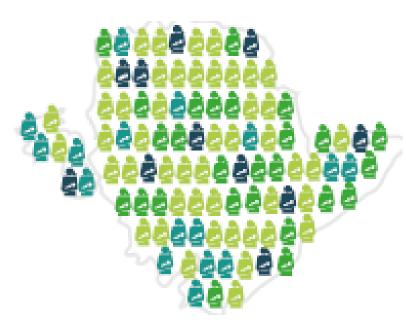


O ACEs 47%

1 ACE 26%

2-3 ACEs 16%

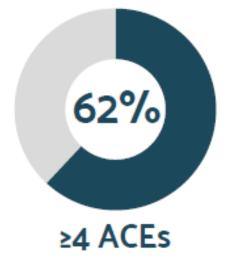
≥4 ACEs 11%



Agreed/strongly agreed with the statement:

I feel like I belong in my community...







Developing a model of ACE enquiry

What these pilots have in common

Not	But
About a score derived from an exhaustive list	Initiating a conversation about need
Developing new care pathways	Using existing care pathways more effectively
Changing the practitioner role	Changing the way information on history is collected



ACE enquiry with health visitors in Anglesey – Ceri Hughes



Evaluation findings





Evaluation objectives

Public Health Wales – Commissioned independent evaluations

- 1. To examine the feasibility of conducting ACE enquiry within different health settings.
- 2. To explore the acceptability of ACE enquiry to service users and practitioners.
- 3. To develop an understanding of how to evaluate the impact of ACE enquiry over larger-scale and longer-term studies.

Methods

Evaluation framework

Feasibility

Acceptability

Process measures

Service user feedback surveys

Focus groups/semi-structured interviews for practitioner feedback

Impact

...outcomes questionnaire (HV); service use data (GP)

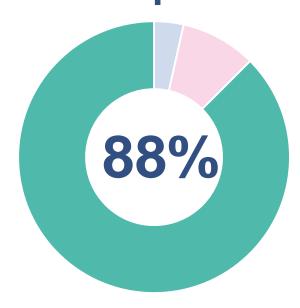


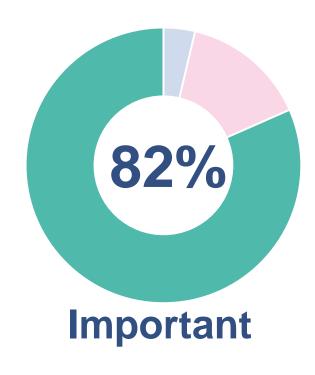
Acceptability

Service user (SU) feedback surveys (N=694)

- Agree/strongly
- Not sure
- Disagree/strongly

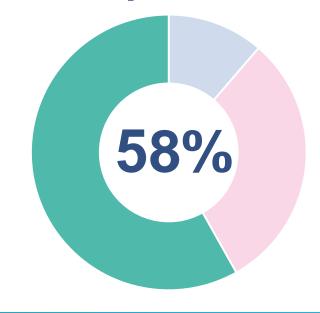
Acceptable





For 56% of those with ACEs, this was the first time they had told a professional or service about these experiences

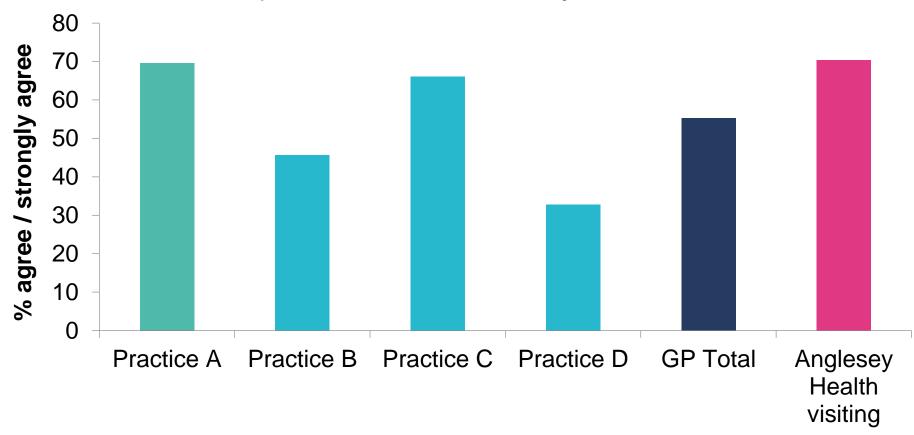
Help and support improved



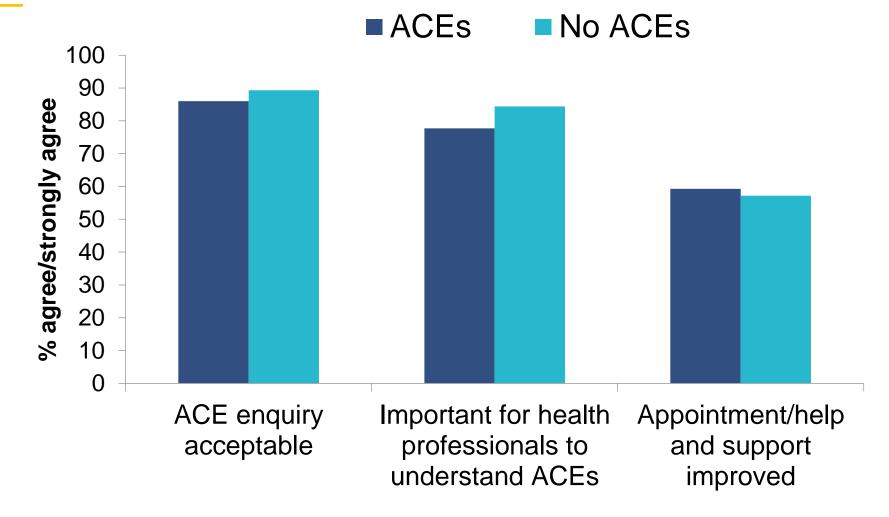
Acceptability

By setting/location

The help and support I received was improved because the health practitioner understood my childhood better...



AcceptabilityBy ACEs





Acceptability

Additional comments from SUs

I think this is a valuable questionnaire. The more information that is available, and the more open people are about problems, the better things can become for future generations.

Questionnaires should be sent out in the post, not completed in the surgery.

I think its important you ask about physical abuse, but what about what you witness at home? For example, someone that is 4 years older than them?

I hope the survey is not an additional burden on GPs – They have enough paperwork!



I think its an excellent idea to ask these difficult questions and is extremely useful. There could have been a question asking whether we felt negative experiences had affected us long term.

I would have preferred to be asked sensitive questions in a more private surrounding. It was an emotional shock and was upsetting to fill in sitting in a waiting room full of strangers...I agree with the survey being done though.

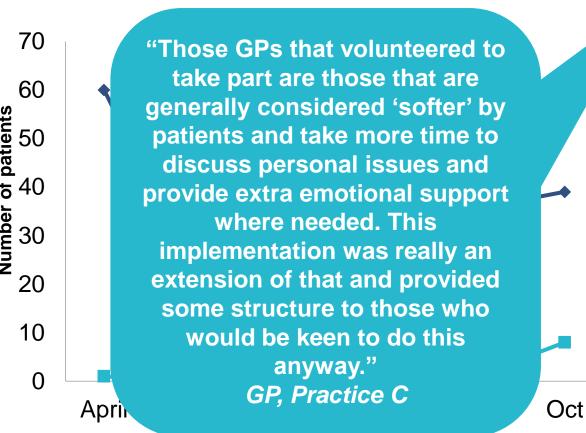
Getting feedback from people who have been affected by one or more of the items on questionnaire might help that person to recognise possible reasons for their own behaviour.



Feasibility

Initial challenges in design and implementation

- Training availability and engagement
- Pilot of the willing and the 'ripple effect' (vs. whole system)
- Identifying eligible service users and adapting booking-in processes [GP]
- Resilience in the system for lateness
 [GP]
- Insufficient 'run-in' time
- Data management and extraction
- Adherence to agreed models of delivery



REACh Pathfinder implementation



Findings - Feasibility and Acceptability Practitioner feedback (N=33)

Process of delivery:

- Structured tool welcomed for: lessening the cognitive and emotional demand on SUs; allowing them greater control over what is disclosed; and supporting privacy in home setting [HV].
- Conversation structured around awareness raising, understanding relationship between early life and later health and wellbeing, or impacts on attachment and parenting.

"Generally patients don't want to volunteer additional information that they think will take up more of the doctor's time. Therefore the structured questionnaire is a good way of delicately asking about a broad range of experiences."

GP, Practice B

"Regardless of their history, the choice to disclose is up to them.

They are in control when they read the questions. They don't fell under pressure to explain, but they can if they want to."

Health visitor



Findings - Feasibility and Acceptability

Practitioner feedback

Impacts on practice:

- Initial concerns about overall increased service demand not realised
- Largely negligible impacts on consultation time; with general understanding that this can always happen in clinical practice
- <u>But</u> different levels of tolerance for delays and concerns about 'tokenistic' delivery
- When delivered by agreed models, no SU requested/was deemed to require onward referral or follow up with a GP; discussions occurred over subsequent HV appointments for some

"Initially the thought of adding \ to "Taking the time to b€ nce explore the ch questionnaire would and did have a massive impact on your workload. Sometimes if you were running behind, it was easy to feel as if you were doing a disservice to it really. You'd say 'any problems?' and they'd say yes and you would start thinking well how "I ca can I deal with this now." Nurse, Practice A /as a supl Simple Till think about it'." HCA, Practice A



Findings - Feasibility and Acceptability Practitioner feedback

Perceived benefits of ACE enquiry:

- Improved relationships increased empathy, trust and openness
- Allowed practitioners to better understand SUs
- Challenged assumptions
- Highlighted particular at-risk groups
- Tentative suggestion of change to SU attitudes
 - Mothers reported thinking differently about how they wanted to parent their children (HV)
 - GP patients help seeking looking for reassurance and the opportunity to talk, rather than further tests or referrals

"They know that there is someone there that can help. Or simply listen. They may not want more than that.

Just someone to listen."

Health Visitor

"Using the questionnaire brought up issues that were incredibly useful. I feel that I know my patients better than I did before. Certainly for patients that have chronic depressive issues."

GP, Practice C



Findings - Feasibility and Acceptability Practitioner feedback

Understanding potential harms:

- Particular challenge understanding outcomes for SUs in GP setting
 - Not possible to gauge 'therapeutic benefit'
 - Lack of follow up mechanisms
- Clinician fears around potential litigation
- Plus...Staff who themselves had ACEs not willing to engage in pilot

"It could've had a detrimental effect though. So they buried it deep, but then we have opened that can of worms. You give them the numbers, but you can't know whether they will actively seek any help."

Nurse, Practice A

Findings – Key differences by setting

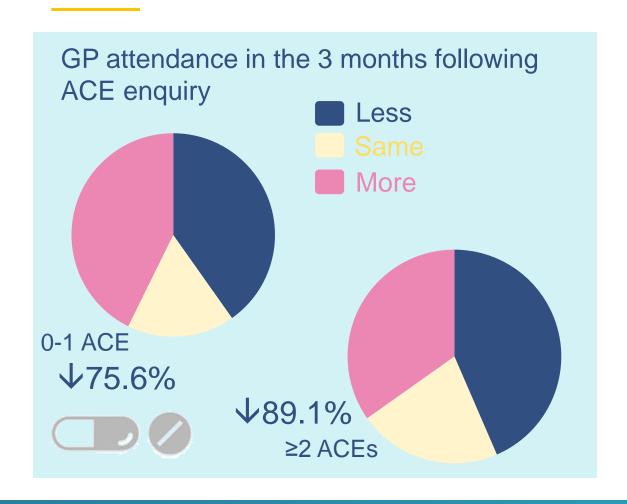
Standardisation vs Flexibility

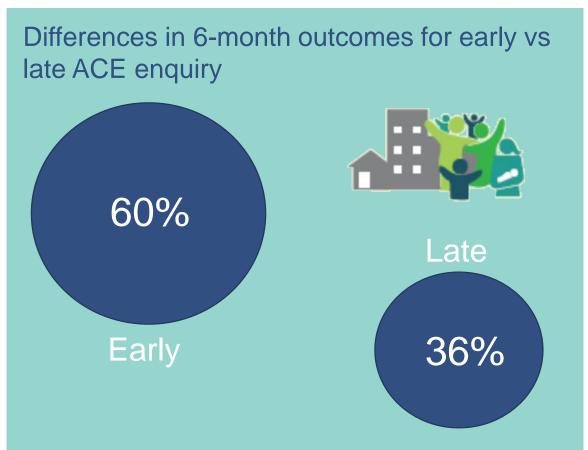
General Practice	vs	Health Visiting
Voluntary clinician participation		Whole-service engagement
Eligibility criteria applied		Universal provision
Flexible delivery adapted to competing demands		Standardised delivery
No clear follow up mechanism		Follow up (6 months)



Understanding impact

Service utilisation / maternal well-being





Next steps?

Current ongoing work and future ambitions



- Welsh Government funded HV pilot extended across south and mid-Wales
 - Stepped wedge implementation from 1st March 2019
 - Evaluation framework focuses on the service user experience and maternal and child outcomes
- New work piloting ACE enquiry in other health settings/populations
 - Cystic Fibrosis annual reviews
 - Fibromyalgia and chronic pain clinics
- Long-term follow up
 - Re-visiting Anglesey cohort



Conclusions

Learning so far

- Initial support for the acceptability of ACE enquiry in healthcare settings among both practitioners and service users
- Suggestion across pilots that asking about ACEs improves the service-user practitioner relationship and increases understanding of wider determinants of health and well-being
- Support for the feasibility of ACE enquiry in the health visiting pathway, although more flexible models may be required
- However, the GP setting presents many inherent challenges for routine delivery with question marks remaining over feasibility at scale
- Experiencing adversity in childhood is related to greater levels of healthcare need in the samples analysed here
- Tentative suggestion of modest reductions in service use and improvements in maternal outcomes following enquiry supports further study



Recommendations

Overall

Further research and evaluation is needed to build on these initial findings and support the development of scaled and sustainable approaches to ACE enquiry in health settings, taking account of points for further refinement and investigation:



Recommendations

Refining models of ACE enquiry

- Conduct detailed assessments of readiness that engage frontline staff, managers and patient representatives
- Ensure continued support is provided to services and tools for monitoring intended delivery (and recording deviations)
- Identify if and how ACE data can be stored (and shared) to be clinically relevant
- Ensure models of enquiry are embedded, supported by all staff and aligned to the values of the organisation
- Ensure entire service user pathway is ACE-informed and that practitioners are entering a genuine dialogue with service users
- Consider models that extend to other population groups (e.g. chronic pain patients [GP]; fathers and other caregivers [HV])



Recommendations

Addressing key emerging research questions

- Further service evaluations needed to explore feasibility and acceptability of different models of ACE enquiry – larger and more diverse samples; longer-term follow up
- Detailed qualitative research with service users to explore potential therapeutic benefit and mechanisms for this benefit
- Research with practitioners to understand how ACE enquiry impacts on professional decision making
- Research into healthcare use behaviours of those with ACEs, to provide a stronger baseline for measuring change
- Consider changes in demand and service user experience across wider health system



With special thanks to: BCUHB colleagues Anwen Last and the health visiting team in Anglesey, Liz Fletcher, Dr Steve MacVicar; and Gabriela Ramos Rodriguez and Mark Bellis (PHW).



Thank you for listening. Any questions?

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