



**CAREHub**

Care-experience Research Edinburgh Hub

# GATEKEEPERS OR FACILITATORS: NAVIGATING CONSENT WITH YOUNG PEOPLE IN SPECIFIC CONTEXTS

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- Ethical Principles and Standards for Developmental Scientists (Society for Research in Child Development, 2021):  
<https://www.srcd.org/about-us/ethical-principles-and-standards-developmental-scientists>
  - “Developmental scientists respect the self-determination rights of participants of all ages to voluntarily choose whether or not to participate in research”
- Seal of Approval Program (International Children’s Advisory Network):  
<https://www.icanresearch.org/work-with-our-youth>
- Guidance informing obtaining information consent for clinical research in children and young people under 16 in Scotland (ScotCRN):  
<https://www.scotcrn.org/informed-consent/>



OVERARCHING  
GUIDELINES

# GUIDING PRINCIPLES

## Children and young people are active agents in research participation

- CYP have a right to decide about their participation
- A responsible adult, usually a caregiver, should be part of the consent process

## Researchers have a responsibility to safeguard CYP

- CYP should be informed, i.e. understand what they are being asked to do
- CYP should not have their safety or wellbeing threatened by consent processes
- Risks of participation should be minimal and justifiable

- Children may feel less able to refuse participation than adolescent or adults (Kassam-Adams & Newman, 2005)
- Children may not always disclose that they don't understand.
  - Is a jumper angrier than a tree? (Waterman, Blades & Spencer, 2001)
- Identifying participants through records can increase suspicion and reduce interest in participation (Stroebe & Stroebe, 1989) – may be an issue for adolescents



INFORMED  
CONSENT

Care-experienced =  
foster/kinship/resident  
ial care and adopted  
CYP

RESEARCH WITH CARE-  
EXPERIENCED/TRAUMATIZED  
YOUNG PEOPLE

2/3 – ¾ of care-  
experienced CYP  
have been exposed  
to early or  
developmental  
trauma including  
abuse and/or neglect

- Extremely marginalized and often institutionalized (both compliant and disengaged)
- “Do **secondary effects of trauma**, such as medical, economic, psychological and social difficulties, **change participants’ ability to provide informed consent** and thus make survivors a particularly vulnerable group needing protection?”
- Does the cultural ethos of avoiding discussion of trauma create unique risks in trauma-related research?”

Newman et al., 2006

- More gatekeepers = more opportunities to passively or actively prevent research
- Protection rackets - Talking about trauma may be dangerous

- Can asking about harmful experiences cause harm?
  - Will asking CYP about self-harm or suicidality make them suicidal or encourage self-harm?
  - Will asking CYP about traumatic experiences re-traumatize them
- Asking CYP about harmful experiences could surface previously unidentified problems and experiences
  - Researchers may underestimate risk of disclosure
  - Gatekeepers will likely bear responsibility for processing a disclosure – added practical and cognitive labour
- Cultural avoidance of acknowledging and discussing harmful childhood experiences
  - 0-22% of mental health patients are asked about abuse histories

Read et al, 2018



OTHER  
POSSIBLE  
RISKS

Systematic Review	Authors	N UK-based studies
Trauma interventions in schools	Fondren et al., 2020	0/62
The Role of Caregiver Psychopathology in the Treatment of Childhood Trauma with TF-CBT	Martin et al., 2019	0/18
Wellbeing Outcomes for Children Exposed to Multiple Adverse Experiences in Early Childhood	Liming & Grube, 2018	0/5
Prevalence of Mental Illness in Child and Adolescent Refugees and Asylum Seekers	Blackmore et al., 2020	0/8
Childhood Maltreatment and Violent Outcomes	Fitton et al., 2020	0/18
Early life adversity exposure and circulating markers of inflammation in children and adolescents	Kuhlman et al., 2020	1/27
Long-Term Health Consequences of Child Physical Abuse, Emotional Abuse, and Neglect	Norman et al., 2012	4/124 (3 MH)
Mental Health Disorders of Children in Foster Care	Engler et al., 2020	1/25
Children's mental health and its predictors in kinship and non-kinship foster care	Xu & Bright, 2018	0/8

# MISSING VOICES


- Does it matter if we rely on international data?
  - Different welfare systems
  - Different cultural and social factors
- Does it matter if we rely on adult report?
  - Poor agreement between prospective and retrospective maltreatment reports and outcomes.
- Can case files provide an acceptable alternative to directly questioning children?
  - Case files miss 72% of abuse histories found by researchers (Read et al., 2018)
  - No opportunity to hear the child's own voice

- 18.7% of parents of stillborn children reported distress after being interviewed, but only 1.2% found the interview distressing and unhelpful.
- Evidence that children and adults find research participation directly related to trauma histories to be helpful

Becker-Blease & Freyd, 2006

- 30% of adult psychiatric inpatients described significant distress after being interviewed about their trauma histories; a further 6.6% terminated the interview early due to distress. 51% thought the interview at least 'somewhat useful'

Carlson et al., 2003



DOES  
ASKING  
ABOUT  
TRAUMA  
CAUSE  
DISTRESS?

## EVIDENCE FOR COSTS AND BENEFITS IN CHILDREN

Author	Sample	Negative effects	Positive effects
Reich & Kaplan (1994)	Community	1% offended by some questions, 3% felt uncomfortable	94% enjoyed the interview, 93% learned more about themselves
Zahner (1991)	Community	12% found some parts 'too personal'	82% found interview enjoyable
Herjanic et al. (1976)	Clinical	19% expressed 'concern', mainly embarrassment	40% found interview helpful to them
Dyregrov et al. (2000)	Community – trauma/adversity	7% of children or adolescents had a negative experience	71% of children or adolescents had a positive experience
Kassam-Adams & Newman (2002)	Clinical - trauma/adversity	13% upset with interview, 2% upset with self-completion questionnaire	-
Carlson et al. (2003)	Clinical - trauma/adversity	30% highly distressed	51% found useful or helpful
Kassam-Adams & Newman (2005)	Clinical - trauma/adversity	5% upset or sad, 10% regretted participation	58% felt good about self, 52% glad was in study

John et al, 2007

# THE CASE FOR CONDUCTING RESEARCH IN TRAUMA WITH CYP

- Estimates suggest that 20-50% of the general population have experienced some form of childhood abuse or neglect
- Asking adults about childhood abuse is an ethical requirement (Becker-Blease & Freyd, 2006)
- The main facilitator of children disclosing is an adult asking (Lemaigre et al., 2017)
- We can only advance our understanding and therefore methods of prevention, intervention and treatment through holistic inquiry of people with trauma experience (van der Kolk, 2016)

# WHAT INFLUENCES GATEKEEPER DECISION-MAKING?

Presenting their organization in a certain way

Modifying the research

Facilitating endorsement of or change in practice

Anxiety and confusion about data protection regulations

Fear of adverse consequences and reputational damage

Time and resource costs

Lay beliefs about research practice

Paternalistic views of childhood

Beliefs about disclosure

- Myths about what is 'allowed' in disclosure processes
- Confusion about the evidence threshold
- Legal or social repercussions
- Lack of training and confidence

Research as inherently harmful?

# THE OPPORTUNITY TO GIVE INFORMED CONSENT...

Mental health and perfectionism in two equivalent schools in Edinburgh (Taylor et al., in submission)

- Parental opt-out consent in one school -> 1 parental opt-out, 3 student opt-outs, leaving 348 participants
- Parental opt-in consent in another school -> 42 participants

Experience of being a carer for a parent with psychosis (Wells, 2017)

- NHS ethics committee required removal of word 'psychosis'

How care-experienced young people navigate peer relationships (Raithatha, 2020)

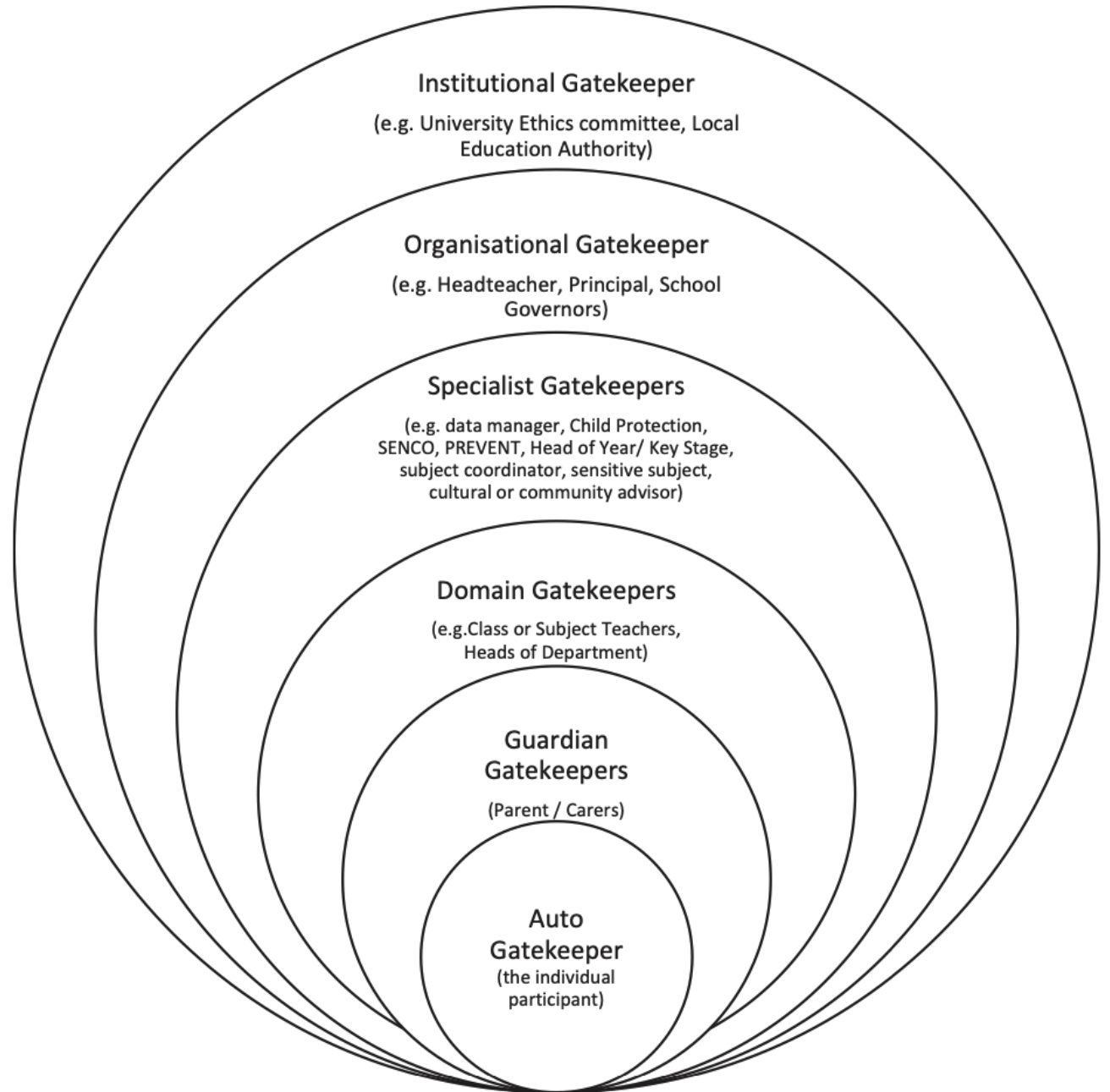
- No direct access to participants
- NHS staff had to provide written confirmation of capacity to consent in advance of contact

How are teachers impacted by receiving disclosures? (Lemaigre, 2016)

- Teachers were too fearful to come forward to discuss experiences

CONDUCT A  
GATEKEEPER  
ANALYSIS

Kay, 2019



**Figure 1.** Potential strata of gatekeepers within an educational context.

# HOW TO ACCESS SPECIAL POPULATIONS

1

Know who your gatekeepers are and factor in time to get to know and engage them in advance

- Fatigue and overwhelm in gatekeepers

2

Be explicit the benefits of your research

- Citizenship part of Curriculum for Excellence
- Giving children a voice

3

Don't under-estimate risks (as perceived by gatekeepers)

- Robust strategy for managing disclosures
- Clarity about who holds responsibility after participation

4

Check researcher competencies and support structures

- Debriefing, supervision and psychological support
- Adequate training and awareness

5

Tackle myths head-on

- KE events
- Introductory videos
- Staff sessions

# CONCLUDING THOUGHTS

- CYP should be treated as stakeholders in research about them
- Gatekeepers are also stakeholders
- Research with CYP defined as vulnerable may need to start with KE, stakeholder engagement, participatory methods with gatekeepers and activities with CYP that create confidence in the competency of the researcher and their research