# Research Protocol: Family Group Conferencing in adult social care

# Research Protocol

## Full title of project

***Family Group Conferencing in adult social care and mental health: exploring how it works and what difference it can make in people's lives***

## Short study title *Family Group Conferencing in adult social care*

## Protocol version number and date. Version 5 14 : 3 : 23

## Research reference numbers

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| **IRAS Number** | 323436 |
| **Sponsor reference number** | ERN_23-0102 |
| **ISRCTN number** | |
| **REC reference number** | |

This protocol has regard for the HRA guidance

## Signature page

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to adhere to the signed University of Birmingham's Sponsorship CI declaration.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publically available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

Chief Investigator:

Signature: ............ Jerry Tew .... Date: ..14....../…3…...../……2023.....

Name: (please print):..........Prof Jerry Tew.................................................................................

## Sponsor statement:

Where the University of Birmingham takes on the sponsor role for protocol development oversight, the signing of the IRAS form by the sponsor will serve as confirmation of approval of this protocol.

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## Key study contacts

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### *Funder*

This project is funded by the NIHR HSDR Programme (project reference NIHR135127).

## Study Summary

| | |
|---|---|
| Study Title | Family Group Conferencing in adult social care and mental health: exploring how it works and what difference it can make in people's lives |
| Study Design | Realist enquiry and cost consequence analysis |
| Study Participants | Staff, service users and family network members |
| Recruitment target | 45 + comparator sample |
| Follow up duration | 12 months |
| Planned Study Period | May 2023 to December 2024 |

***Research question***

How and where is Family Group Conferencing (FGC) for adults and mental health being delivered, how may practice model(s) be characterised in terms of contexts, mechanisms and outcomes, and what is its effectiveness in terms of costs and consequences?

***Aims***

1. To develop and test underpinning Programme Theory for FGC and hence develop fidelity measures and practice standards
2. To evaluate both shorter and longer term impact of FGC for a sample of individuals and their family networks – including a preliminary analysis of costs and consequences as against a matched comparator group receiving 'service as usual'.

## Funding and support in kind

| **FUNDER(S)** | FINANCIAL AND NON FINANCIALSUPPORT GIVEN |
|---|---|
| National Institute for Health and Care Research – Health Service and Delivery Research programme<br><br>University of Southampton<br>Alpha House, Enterprise Road<br>Southampton SO16 7NS | £ 954,006.80 |

## Role of study sponsor and funder

Sponsor has overall responsibility for conduct of study in line with NIHR governance requirements

## Roles and responsibilities of study management committees/groups

Study will be overseen by a Study Steering Committee in accordance with HIHR governance requirements. Apart from the Chief Investigator, all members will be independent. Membership is subject to approval from NIHR.

The study will be advised by a Lived Experience Advisory Panel

## Protocol contributors

Protocol written by Chief Investigator and approved by Sponsor and funder.
Lived experience researchers contributed to the research design.

**Study flow chart** - see Page 29

# Study protocol

## Full title of project

***Family Group Conferencing in adult social care and mental health: exploring how it works and what difference it can make in people's lives***

## Short study title *Family Group Conferencing in adult social care*

## 1 Background

Originating in New Zealand, FGC has become established as a practice in Children and Family services in the UK (1). Over recent years, the approach has been extended into adult social care and mental health services, both in the UK (2) and internationally (3). FGC involves bringing together an individual with family and/or other members of their social network in order to decide on a plan whereby to resolve a current difficulty or challenge – e.g. around organising support, enabling recovery or ensuring safety. It is facilitated by an independent co-ordinator and comprises 3 stages: i) preparatory work with the individual and each family/network member to elicit their involvement and help them to establish what they each want out of the process; ii) the Conference itself which usually starts with information sharing and discussion with any professionals involved before there is 'private family time' in which the individual and family/network members share ideas and decide on a plan, and iii) subsequent review meeting(s) to check out how the plan is working and adapt it if appropriate.

FGC has been seen to offer a more inclusive approach to decision making which can mobilise the strengths and resources that may potentially exist within people's family and social networks – and therefore fits well with wider policy and practice developments around strengths-based practice (4). The approach may be used, not only when people themselves may have full capacity, but also where, in line with the United Nations Convention on the Rights with Persons with Disabilities (UNCRPD), people may require support for their decision making and it is appropriate for family, friends and others to be actively involved to help the individual fully participate. However, apart from some local evaluations (18, 21, 22, 32) there has so far been no larger scale UK study to determine how FGC works, and for whom it works best, in adult social care or mental health service contexts.

A brief review of the literature was conducted with searches of the following databases (ASSIA, HMIC, IBSS, Scopus, Social Care Online, Social Policy & Practice and Social Science Citation Index). This was supplemented by inclusion of wider contextual and policy literature – and also 'grey' literature known to the research team (principally local service evaluations). The following databases were searched (2010 to present), using the search term strings family group conferenc* AND adult; family group conferenc* AND supported decision making; family group conferenc* AND best interest*; family group conferenc* AND mental OR psychiatr*; family group conferenc* AND older; family group conferenc* AND disabilit*; family group conferenc* AND social care; and family group conferenc* AND strength* OR asset*.

This review has highlighted the relative paucity of research on FGC in adult social care and mental health contexts – primarily due to this being an area of relatively recent development, both in the UK and internationally. A recent overview concluded that 'the studies reviewed into the effectiveness of FGCs in adult services are mostly small-scale and largely short-term, have used a range of study designs, and were located in different jurisdictions whose legal, health and social care systems may have variously impinged on social welfare, care provision and individual wellbeing' (5) – hence a lack of a sufficiently coherent and consistent evidence base.

A number of local evaluations of adults and mental health FGC services have been conducted in the UK (18, 21, 22, 23, 32), and FGC has also been included in wider studies of family inclusive (24) and preventative approaches in adult social care (19). Overall, findings have tended to be positive, and a consistent finding is that FGC can enable people to resolve difficulties relating to care and support arrangements – often by mobilising support arrangements that involve a wider 'circle of support' and/or by resolving issues between people which had made it harder for them to pull together (18,19). Plans devised by the person and their network can reduce or delay the need for more costly and intensive service provision (18), or can employ care services in ways that are more acceptable and empowering.

However, depending on social and organisational context, reported improvements may be quite modest (16) and not be sustainable at 12 month follow-up (17). A significant proportion of those referred for FGC may decide not to proceed to a full Conference – sometimes because they are unwilling to invite key people from their social network or share shameful feelings or grievances (52). Issues have also been raised about the suitability of FGC for certain minority groups – particularly where concerns around family and community shame may be foregrounded (53, 54).

Many individuals and families reported that they were empowered by the process (putting them 'in the driving seat'), and that, as a result, the individual had a better quality of life with a wider network of social capital and support – although this was not the case in every instance (24). This suggests a need to research in more depth the 'how' of FGC, with a clearer theoretically-informed understanding of FGC process (25). Mechanisms of change may, in some instances, include mobilising and remobilising social networks (55), the opportunity to restore damaged or estranged interpersonal relationships, or to increase understanding within them (including the sharing of shameful experiences) (24, 52). However, there can also be concerns that FGC processes – and ownership by the individual with support from their family/network - may become subverted by a professional system that, directly or indirectly, seeks to set the agenda for the Conference process (26).

FGC has been piloted as an approach to ensuring better safety for vulnerable adults within the wider Making Safeguarding Personal initiative (27) and its value in this and related legal contexts is gaining increasing interest. The United Nations Convention on the Rights with Persons with Disabilities (UNCRPD) requires signatory countries (including the UK) to adhere to its provisions. Of particular note here is Article 12 which enshrines in law for the first time that all people, regardless of disability, have legal capacity and thus states are required to implement measures to facilitate the expression of that legal capacity and ensure the person's will and preferences are upheld in any decision making process (UNCRPD 12(4)). As a consequence, there is increasing interest in developing mechanisms for 'supported decision making' whereby 'the person with disabilities is supported wherever possible to make a decision and exercise their legal agency even in when they lack the ability to do so themselves' (28) - and the involvement of family or significant others may play an important role in enabling this.

A meta-synthesis of evidence relating to family involvement in decision making for people with dementia in residential care (29) found that, while many (but not all) families wanted to be involved, they encountered numerous difficulties, including accessing professionals, having time to discuss information with them and being actively involved in decision making. Such experiences of exclusion may be even more acute for members of minority communities. The review found wide variation in terms of professional attitudes and processes for involving families and exchanging information, issues which FGC is designed to address. The proposed research thus provides a very valuable and timely opportunity to further investigate the contribution FGC may make towards enabling all those involved in providing support to express their ideas and preferences, and for plans and proposed solutions to be embedded in the reality of people's day-to-day lives.

There has been considerable contention as to how FGCs should best be evaluated (5). Some would argue that simply enabling a family to devise their own plan for support or protection is a sufficient measure of a 'good' outcome, while others would seek evidence that the plan satisfied the concerns raised by professionals and was sustainable in the longer term. What individuals and family members may see as important may differ substantially from the professionals' agenda (33).

Where attempts have been made to analyse costs and savings, estimates have suggested net savings in terms of subsequent care management and service provision of between £1000 and £7000 per FGC (18, 21). However, there remains 'a shortage of reliable research regarding their impact' (34). There is also insufficient clarity as to when and in what sorts of circumstances FGC should be offered – although there are strong indications that the approach is more effective when offered 'upstream' when difficulties are first emerging, rather than being used as a last resort (35).

Significantly more research has been undertaken in relation to FGC with children, and a Randomised Control Trial is currently being undertaken to research FGC for children who would otherwise be facing care proceedings (36). However, this study can only be of limited relevance to FGC practice in adult social care or mental health, where the legislative and service contexts are very different, and other research has highlighted significant differences in terms of context and process (37,38). With adults social care and mental health, it is typically offered as part of an emerging range of strengths based and preventative approaches, rather than as an alternative to statutory intervention (2,19) – and hence outcome measures such as the avoidance of statutory intervention are not relevant in such contexts.

Internationally, there have been some larger scale studies and evidence reviews of FGC in adults and mental health contexts. However, this is yet to yield a very definitive evidence base – mainly due to the heterogeneity of contexts and approaches to practice (as there are, as yet, no agreed fidelity principles or standards). For example, a recent systematic review (39) used a more generic definition of family group decision making that included a range of approaches to facilitated decision making, not all of which are congruent with the principles of FGC (such as the opportunity for private family time).

Underlying this, there is insufficient theoretical understanding of how FGC can offer (and steer) opportunities for positive change through the process of coming together and being able to take charge of, and carry through, decisions that were arrived at collectively. Without such programme theory, it is not yet possible to reach judgements as to how, for whom and in what circumstances FGC may be expected to be effective in an adult social care context – and hence to evaluate whether or not services are actually delivering to such expectations in practice.

## 2 Rationale: why this research is needed now

While the majority of care and support for adults is provided by family, friends and neighbours (20), there are often no effective mechanisms in place whereby they can be involved as full participants in planning and decision making alongside the person with support needs. This can contribute to stress or breakdown in caring arrangements. Professionally-led decision making can often focus around what can (or cannot) be offered in terms of statutory intervention or service provision, rather than on how those directly involved can be enabled to have a better life through finding solutions that work for them.

As highlighted in the Chief Social Worker's Report (4), FGC may contribute to the delivery of strengths-based and preventative practice – in line with the Care Act and subsequent draft Guidance on 'Thinking Family' (40). It may offer an effective approach to safeguarding (38) in the context of the Making Safeguarding Personal agenda (27), and to supported decision making in line with Article 12 of the UNCRPD. Although an increasing number of local authorities and other organisations have been expressing interest in developing FGC services for adults with social care or mental health needs, a survey has found that family or network focussed approaches such as FGC were only being offered in a small minority of local authorities (19).

FGC represents a promising approach which an increasing number of local authorities and Health Trusts are seeking to take forward. However, there is still limited understanding of exactly how it may work, who may benefit most, what outcomes are achievable (and at what cost) and what social and service contexts may support its longer term effectiveness.

## 3 Theoretical framework

The overall Project design will use a realist approach (8) to analyse the relationships between contexts, mechanisms and outcomes across different FGC services in order to develop, test out and refine its underpinning programme theory, and to evaluate its impact.

## 4 Research question, aims and objectives

### *Research question*

How and where is Family Group Conferencing (FGC) for adults and mental health being delivered, how may practice model(s) be characterised in terms of contexts, mechanisms and outcomes, and what is its effectiveness in terms of costs and consequences?

### *Aims*

1. To develop and test underpinning Programme Theory for FGC and hence develop fidelity measures and practice standards
2. To evaluate both shorter and longer term impact of FGC for a sample of individuals and their family networks – including a preliminary analysis of costs and consequences as against a matched comparator group receiving 'service as usual'.

### *Objectives*

i. To scope and characterise FGC activity in adults' and mental health services, the contexts and circumstances in which it is offered, and what individuals, family/network members, practitioners and commissioners see as valued outcomes – and out of this to establish preliminary programme theory for model(s) of practice

ii. To examine what may be barriers and facilitators to the delivery and uptake of FGC, with a particular focus on the perspectives of those who have experienced FGC, and on accessibility and acceptability to members of different ethnic and cultural communities.

iii. To examine the process of FGC for a sample of family/network groups across different services in order to test out and further develop programme theory – what works for whom, how and in what contexts.

iv. To evaluate the impacts and outcomes of FGC, their sustainability and cost consequences – with a particular focus on wellbeing, capability, supportiveness of relational networks and use of services.

v. To use the above findings to establish consensus as to the underpinning Programme Theory for effective FGC practice and translate this into fidelity criteria, relevant outcome measures, standards and guidance.

**vi.** To share learning through knowledge exchange with an actively engaged community of policy and practice, including the development of e-learning materials for practitioners, organisations and families.

### *5. Study design and methods of data collection and data analysis*

The Project comprises four Work Packages (WP) that are detailed below and their sequencing is set out in the flowchart on page 28.

In line with the philosophical basis of FGC, all Work Packages and the knowledge arising from them will be co-produced with people with lived experience of social care and mental health services in order to ensure that experiential knowledge is foregrounded and user voices are genuinely heard (41). We will use standards for service user involvement in research developed by the National Survivor User Network (NSUN) (42) as well as being guided by the UK standards for public involvement in research (43).

We are aware that mainstream research can fail to challenge its white-centred core (44) – although in this instance, the fact that FGC was originally developed in a non-white context may be helpful. Many survivor researchers have expressed a desire to change this (41) and we will work to prioritise the diverse voices of people with lived experience within the structures, processes and activities of the project – e.g. in the facilitation of consultative events and processes.

It is recognised that some restrictions due to covid-19 may be in place during the research. This will affect both FGC practice and the research process. While there have been restrictions, FGC practice has continued, with Conferences taking place online or with hybrid arrangements such as a household being together in the same room and others (professionals and wider family/network) joining online. Irrespective of covid-19 restrictions, a substantial proportion of meeting and research interviews will be conducted online (or by telephone) – as this can be more convenient and online platforms, such as Zoom or Teams, are now more familiar to people. If necessary, all the research can be conducted in this way – although our preference will be to have substantive face-to-face activity as part of all Work Packages.

### *WP1: Scoping and characterisation of model(s) of FGC practice in adults and mental health services, including preliminary programme theory and expected outcomes. University of Birmingham ethical approval obtained for this work package. Ethics ref: ERN_22-0818*

Objectives (i-ii) (0-6 months). Co-leads: Mary Mitchell, and Abyd Quinn-Aziz, with input from Vicky Nicholls, Tim Fisher and T K Vincent

This WP will build upon the process of consultation and collective writing of Good Practice Guidance currently being co-ordinated by T K Vincent for the FGC Adults Practice Network. This work will provide a preliminary description of the model(s) and process of FGC within adult services, and what practitioners and others across the sector currently see as best practice. It will also have started to scope the various client groups currently being offered FGC, and what may be being seen as appropriate outcomes that FGCs should be aiming to achieve.

Particular research questions:

a) What FGC activity is taking place across the UK and how may this be characterised? What are the elements that comprise the process and are there different adaptations of models in particular locations / service contexts?
b) What is the evidence around 'user' experience. What sort of outcomes are people looking for from FGC? What do people appreciate or dislike about FGC process?
c) How accessible and acceptable is FGC to members of different communities?
d) How well does FGC activity fit with wider policy and service contexts– e.g. Making Safeguarding Personal, strengths based practice, mental health recovery? How well do wider service contexts support the implementation of families' plans? What are the barriers and facilitators to the delivery and uptake of FGC within organisations?
e) What are the range of potential positive outcomes that may be achieved though FGC – and how are these understood and prioritised by different stakeholders (including service users and family members)? Which outcomes may be seen as important across all service contexts and which may be context-specific?
f) How can we best characterise underpinning programme theory as to how contexts, processes and mechanisms link to outcomes – who may it best work for and in what social, cultural or service contexts?

The Work Package will comprise:

1.1 Realist synthesis of relevant research, policy and practice literature – including 'grey' literature and first person accounts (6) using the Rameses 1 reporting framework (7). The aim will be to include all relevant UK and international literature, using both database searches and a 'call for evidence' via Twitter, the FGC Research and Practice Network website (see WP5) and user-led or carer-led networks (eg. NSUN, Carers UK and People First). There will be a primary focus on FGC in adults and mental health services, but also inclusion of more generic theoretical or policy literature relating to FGC. Search terms will be reviewed in conjunction with lived experience researchers within the team to ensure that themes of empowerment and user experience are fully captured in the search methodology. The selected material will then be assessed for rigour, validity and relevance to the research questions using criteria that will be coproduced between academic and lived experience researchers. A minimum of 20% of the overall sample of literature will be independently assessed by both an academic and a lived experience member of the research team.

1.2 Online survey of local authorities, voluntary sector and NHS providers undertaking FGC activity. Survey questions to be informed by 1.1 (above) and specifically linked to research questions (a), (c), (d) and (e).

1.3 Online survey / telephone interviews (according to preference) with individuals and family members with some involvement with different FGC services – to be accessed via those organisations surveyed in 1.2. This will include people who had been offered but had declined to have a full Conference, or where it was not seen as having facilitated positive outcomes – and organisations would be asked particularly to encourage uptake by members of BAME communities. Survey questions to be informed by 1.1 (above) and specifically linked to research questions (b), (c) and (e). In addition, BAME community organisations with an interest in adult social care or mental health will be consulted as to their views on the accessibility or otherwise of FGC to members of their communities.

1.4 Iterative development of preliminary programme theory to characterise the linkages between social and organisational contexts, processes / mechanisms and hoped-for outcomes. This would be informed by:

   a) Telephone / online interviews with a purposive sample of around 15 key informants drawn from the respondents to the above online surveys, including practitioners, service managers, service users and family members (including those reporting less favourable experiences).
   b) Deliberative Forum (45), co-facilitated with lived experience researchers to ‘sense check’ emerging themes and refine preliminary components of programme theory and anticipated outcomes. This would involve around 30 participants working between small groups and the larger group to achieve consensus where this is possible, but also important to record disagreement or differences in views and experiences. The structuring of the small groups would be designed to provide safe spaces for the articulation of potentially marginalised voices. Participants to include individuals and family members with experience of FGC; practitioners, managers and policy makers; and representatives from BAME, LGBTQ and other community organisations with an interest in wider experience of adult social care and/or mental health services.

### *WP2: Family/network case studies – Refining programme theory, and evaluating experience and outcomes, including costs, consequences, and sustainability*

Objectives (iii-iv) (6-27 months) Co-leads: Michael Clark, Philip Kinghorn (economic evaluation) and Sharanya Mahesh. A researcher with lived experience will be assigned to each research site and will undertake many of the interviews with individuals and family/network members and all observations of Conferences.

Drawn from (provisionally) 3 services, we will track the experience of a sample of individuals and one or more of their family/network members that went through to a full Conference – around 25-30 cases in total – from baseline (acceptance by the FGC service) with a primary follow-up at 9-12 months, to assess whether any positive changes are observed (and sustained). In addition, we will track the experience of a sample of around 12-15 individuals and one or more of their family/network members who were referred for and met the criteria for the FGC service, but did not carry through to have a full Conference – around 12-15 in total – again with primary follow-up at 9-12 months. We will seek to ensure that the sample of families / groups is as inclusive of diverse ethnic minority groups as possible.

Alongside this, for the cost / consequence evaluation, we will recruit a matched comparator sample of 25-30 people and their family/network who will be receiving a similar social care or mental health support (‘service as usual’) as those selected to be part of the study sample who will be receiving FGC in addition to this. They will be selected on the basis that they are (a) from the same service user group (e.g. older people, physical disability etc), (b) have identified family or other support network and would have met the acceptance criteria for the FGC service and (c) have similar demographic characteristics (age group, gender, BAME / non-BAME). The comparator samples will also be followed up at 9-12 months.

Particular research questions:

(a) How well does the preliminary programme theory describe the observed relationships between contexts, mechanisms and outcomes?
(b) What aspects of the process be may be seen as influencing outcomes – and what is valued (or disliked) by participants? Is this different for members of minority communities?
(c) What outcomes are achieved in relation to (a) wellbeing, control and opportunity, and (b) restoration or enhancement of personal, family and social relationships
(d) What are the costs and consequences of FGC in terms of (a) enhanced wellbeing and opportunity and (b) use of social care and health services, and broader societal costs?

### *Overview of research methods*

Employing a realist enquiry approach as specified in the Rameses 2 Report (9), we will focus on the relationships between contextual factors, mechanisms of change and outcomes within each case study. Building on the methodology used in an earlier study (24), a range of interview, observational and measurement data will be triangulated for the analysis. All observations, and much of the interviewing, will be undertaken by researchers with lived experience – who will also take part in the analysis of the data and distillation of emergent themes (41).

### *Outcome measures*

Of greatest interest is what individuals themselves identify as their hoped-for outcomes – and whether these are achieved. These will be collated at the start of the FGC process and individuals' assessment of progress towards these outcomes will be recorded at subsequent follow-up points. Given the likely heterogeneity and differences in ambitiousness in the sorts of outcomes that people may hope for from a group process, it is not considered appropriate to use a measure such as Goal Attainment Scaling.

For the samples of those receiving a full FGC service, outcomes will be assessed in terms of immediate impact (at 4-6 weeks after a Conference has taken place) and longer term impact (after 9-12 months), in order to capture impacts on wellbeing and support arrangements that may take longer to bed in, and also to see whether any early positive impacts are sustained.

The sorts of generic outcomes that may be expected from FGC, for both the individual and family members, include (i) enhanced sense of being in control and having opportunities to undertake valued roles and activities, and (ii) better relationships and social connectedness. The former broadly correspond with what may be termed the eudaemonic or 'flourishing' aspect of wellbeing, and, at a theoretical level, link well to concepts of 'capability' (47). A capability approach fits well with the core philosophy of the Care Act as it emphasises the importance of people's ability to make their own choices in terms of lifestyle, social opportunities and use of support and care, and the actual availability of such valued options within their social world.

Therefore, the primary outcome measures for the study as a whole, and also for the economic evaluation, will be capability based measures of wellbeing that have been validated within the general population, rather than just with people connected to social care or health services – ICECAP-O and ICECAP-A. These brief 5 item measures have been recommended for use by NICE (13), and SCIE has emphasised their relevance and potential value in terms of capturing outcomes in terms of such a broader appreciation of quality of life for economic evaluations of services (14). Although ICECAP–O was originally validated for older people, it has also been used more widely with other groups of people experiencing disabilities (15) and will be the preferred version of the measure for the individuals who are the centre of the FGC process. ICECAP-A has been validated with adults of working age and will be the preferred measure for family and network members.

Although FGC is not set up to be therapeutic, it is possible that the process of bringing people together around an individual may serve to enhance the quality and supportiveness of their personal and social relationships. In order to assess to what extent this may be the case, and whether any enhancement is sustained, we will use a recently validated brief version of the Social Provisions Scale to measure individuals' subjective valuation of the quality of their personal relationships and social connectedness (31). This comprises 5 items taken from the original 24 item Social Provisions Scale (30) and assesses attachment, availability of support, social integration, reliable alliance and reassurance of worth.

Complementing this, family/network member(s) will complete the validated Carer Experience Scale (CES) (12), which will be used in preference to measures of 'carer burden', which can fail to represent the complexity, mutuality and potential for satisfaction that may be features of caring relationships.

Alongside obtaining data on process and outcomes, we will also conduct an economic evaluation, using a cost consequence analysis, with matched comparator groups receiving 'service as usual'. We will assess, over a 9-12 month follow up period, the relative trajectories of each, focusing on monetised benefits (using values linked to ICECAP and CES measures) and costs associated with the use of social care and health services.

## Data collection

### ***Staff and stakeholders***

#### *Managers and stakeholders*

In order to understand the wider service context within agencies, and how FGC fits within this, in each site we will conduct interviews with key managers/commissioners including the Principal social worker or senior equivalent.

#### *FGC Coordinators*

For each family/network in the FGC and Non-Conference samples below, we will ask to interview the FGC Coordinator to elicit their perspective on process and outcomes. Identifiable information will only be discussed in relation to those cases where we have received consent from the service user and family regarding their information being discussed in the interview.

### ***Individuals and family networks***

As part of the consent process, permission will be sought from individuals to obtain data from the local authority or NHS Trust that is providing the FGC service (as detailed below). Members or the research team will not have direct access to service user / patient records and the relevant data will be extracted either by a member of the FGC service or by a member of staff employed by the local authority or NHS Trust in an information capacity that would normally have routine access to such care records as part of their employed role.

Estimates of service costs will use standardised costs associated with the services being accessed.

### *FGC Sample*

For each family/network case study, we will collect the following data.

- At point of acceptance to FGC service (baseline):
  - Summary data on individual from local authority / NHS Trust – age, gender, ethnicity, service user group
  - Relevant text from referral as to current challenges and hoped-for outcomes

- At baseline and at 9-12 month follow-up
  - Available data from local authority / NHS Trust on current level of social care and health service use by individual

- At baseline, 4-6 weeks and at 9-12 month follow-up, brief survey questionnaires:

For individuals, this will comprise:

- a free text / open question as to what would be their hoped-for outcomes from the FGC process (at outset) and to what degree these have been achieved at the two subsequent time points
- 5 question ICECAP-O measure of capability / wellbeing (10)
- 5 item Social Provisions Scale (quality of personal and social relationships) (31)
- A self-report of their level of use of social care and health services at point of acceptance and at 9-12 month follow up (where data not available from local authority / NHS Trust), including their use of unplanned health services which may indicate both points of personal crisis and significant cost, such as A&E visits.

For one or more of their family/network members this will comprise:

- a free text / open question as to what would be their hoped-for outcomes from the FGC process (at outset) and to what degree these have been achieved at the two subsequent time points
- 5 question ICECAP-A measure of capability / wellbeing (11)
- 6 item Care Experience Survey (12).

At baseline and at 9-12 month follow up, completion and return would be either by post, via return email or via a telephone interview, according to preference.

- Permission from individuals and family members will be sought to observe all or part of the Conference, potentially including private family time, but this will be optional.

- 4-6 weeks after the Conference (to coincide with FGC Review meeting where possible), separate face-to-face or online interviews with the individual, 1-2 family/network participants and (with the permission of the individual and family/network participants) the FGC co-ordinator.
  - In order to test out and develop the Programme Theory, these interviews will explore participants' experience of the FGC process, whether and how this had helped shape a likely positive future, how (and whether) the family's plan was taking shape and

being supported, and what wider contextual factors were either enabling or inhibiting, hoped-for changes.

- Individuals will be asked to rate their current capability / wellbeing using the 5 question ICECAP-O measure and the quality of personal and social relationships using the 5 item Social Provisions Scale. In addition a more detailed understanding of the person's relational networks, and how these may have changed, will be gathered using an eco-mapping approach (46). They will be asked about their current use of social care and health services and how this may have changed as a result of the FGC process.

***Non-Conference Sample***

For each family/network case study, we will collect the following data.

- At point of acceptance to FGC service (baseline):
    - Summary data on individual from local authority / NHS Trust – age, gender, ethnicity, service user group
    - Relevant text from referral as to current challenges and hoped-for outcomes
- At baseline and at 9-12 month follow-up
    - Available data from local authority / NHS Trust on current level of social care and health service use by individual

- At baseline and at 9-12 month follow-up, the individual and one or more family / network members will each complete a brief survey questionnaire. Completion and return would be either by post, by return email or via a telephone interview, according to preference.

For individuals, this will comprise:

- a free text / open question as to what would be their hoped-for outcomes from the FGC process (at outset) and to what degree these have been achieved without a Conference at 9-12 month follow-up
- 5 question ICECAP-O measure of capability / wellbeing (10)
- 5 item Social Provisions Scale (quality of personal and social relationships) (31)
- A self-report of their level of use of social care and health services at point of acceptance and at 9-12 month follow up (where data not already available from local authority / NHS Trust), including their use of unplanned health services which may indicate both points of personal crisis and significant cost, such as A&E visits.

For one or more of their family/network members this will comprise:

- a free text / open question as to what would be their hoped-for outcomes from the FGC process (at outset) and to what degree these have been achieved at the two subsequent time points
- 5 question ICECAP-A measure of capability / wellbeing (11)
- 6 item Care Experience Scale (12) ) and indication of current levels of informal care activity.

- At point of exit from FGC service, face-to-face or online interviews with the individual, 1-2 family/network participants and the FGC co-ordinator to explore

- their perspectives on what did and did not work in preparatory phase of the FGC process,
- the reasons why they did not choose to have a full Conference,
- the extent to which the preparatory process had helped shape a likely positive future, and
- what wider contextual factors, and particular mechanisms within the overall FGC process, had either contributed to, or inhibited, hoped-for changes.

### *Comparator sample*

For each family/network, we will collect the following data.

- At point of acceptance into the study
    - Summary data on individual from local authority / NHS Trust – age, gender, ethnicity, service user group
- At baseline and at 9-12 month follow-up,
    - Available data from local authority / NHS Trust on current level of social care and health service use by individual
- At baseline and at 9-12 month follow-up, the individual and 1-2 family / network members will each complete a brief survey questionnaire. Completion and return would be either by post, via return email or via a telephone interview, according to preference. For individuals, this will comprise:
    - a free text / open question as to what would be their hoped-for outcomes for the coming 9 months (at baseline) and to what degree these have been achieved (at 9 month follow-up)
    - 5 question ICECAP-O measure of capability / wellbeing (10)
    - 5 item Social Provisions Scale (quality of personal and social relationships) (31)
    - A self-report of their level of use of social care and health services at point of acceptance and at 9-12 month follow up (where data not already available from local authority / NHS Trust), including their use of unplanned health services which may indicate both points of personal crisis and significant cost, such as A&E visits.

For one or more of their family/network members this will comprise:

- a free text / open question as to what would be their hoped-for outcomes for the coming 9 months (at baseline) and to what degree these have been achieved at follow up
- 5 question ICECAP-A measure of capability / wellbeing (11)
- 6 item Care Experience Survey (12).

## Data analysis

Starting with the constructs outlined in the preliminary Programme Theory, for each family/network case study a deep description of Context-Mechanism-Outcome configurations will be derived from triangulating between the various sources of data. Given that the sampling will take place before the FGC process is undertaken, it is likely that the sample will include instances where the approach has been both more and less successful – with indications from the data as to what contexts or processes may have contributed to such differences. A particular focus will be on what factors influenced whether any benefits were sustained over the follow-up period – and on the longer term impact of FGC in terms of service use and other costs. Analysis of common factors, configurations and differences will then be undertaken, firstly between all the case studies for a specific site, and then between sites. Through an iterative process, the Programme Theory will be developed and refined to take account of our empirical findings in order to derive a more comprehensive picture of what works for whom, how and in what circumstances. Where significant differences in approach emerge between sites, more than one such configuration may need to be included in the overall Programme Theory.

Analysis of the data will also give an opportunity to investigate

(a) the degree to which the achievement (or otherwise) of people's hoped-for outcomes was reflected in measures of capability / wellbeing and/or quality of personal and social relationships and carer experience - both in the short term and at 9-12 month follow-up.
(b) the degree to which changes in overall capability/wellbeing were associated with changes in quality of personal and social relationships - indicating the extent to which the *process* of FGC may be important in its own right (in terms of bringing people together), as well as effectiveness of the plan that was agreed
(c) whether improved capability/wellbeing for individuals was associated with similar improvements in the quality of life of family/network members, or whether a better life for the individual may be at the expense of increased stress for those who support them.

As there are scoring systems available for ICECAP and CES measures (allowing a quantitative summary of responses, reflecting population preferences), we will compare scores at baseline and follow-up, and compare changes between these two time points for the FGC, Non-Conference and Comparator 'service as usual' samples. Other outcomes (informed by WP1) may have ordinal or more narrative responses (hence our choice of cost-consequence analysis as a framework, allowing the combination of complex cost and outcome data, not necessarily expressed in quantitative units).

We will capture resource use that is likely to have a significant impact on costs from an NHS/PSS perspective (such as unplanned/emergency healthcare), and attribute monetary costs to these from published sources or grey literature. Some local authorities 'buy in' FGC from contracted providers and we will explore the range of costs/prices in the survey of local authorities (WP1). We will also seek the expert opinion of contacts from local authority sites to cost other elements of social care resource use, where reliable and generalisable costs are not available in the literature.

We will map out the potential pathways, for example: (i) care as usual; (ii) eligibility for FGC, and acceptance; (iii) eligibility for FGC, but rejection by the individual or family. We will summarise in tabular or narrative form, potential costs and outcomes that can be attributed to/associated with each pathway; and explicitly acknowledge where we have identified/captured credible and generalisable empirical evidence of these costs/outcomes and where there are gaps in current knowledge that will need to be addressed through further research. Costs and capability / wellbeing outcomes will be presented within a cost-consequence analysis (CCA). Monetary costs (from an NHS and Personal Social Services perspective) will be identified from both contacts within the case study local authorities and from published sources (such as PSSRU Unit Costs of Health and Social Care). Costs will be assigned to NHS/Personal Social Service resource use, identified and recorded during WP2. Outcomes will be included for which there is a meaningful summary score (i.e. ICECAP-A and ICECAP-O), but also where the definition of outcomes is of a qualitative nature. We will explore expectations of what outcomes would have been without FGC, but recognising the speculative and potentially biased nature of such information

### *WP3: Expert consultation to finalise definitive Programme Theory, fidelity criteria and outcomes*

Objective (v) (24–30 months) Co-leads: Jerry Tew, Miranda Johnson and Emma Ormerod
This work package will revisit the preliminary specification of programme theory from WP1 in the light of the analysis and findings of WP2, in order to derive a more definitive

characterisation of FGC model(s) in adult social care and mental health – and, out of this, to establish appropriate fidelity criteria and outcome measures.

Particular research questions:

- What are the core ingredients, processes and contextual factors for effective adult FGC practice?
- How can these be translated into consensus fidelity criteria, standards and guidance?
- In the light of findings from WP1and WP2, what is the consensus around what are the most relevant outcome measures – both generic and specific to particular service contexts?

Employing a similar approach to that used by Jeffery et al (48), we will use an iterative Delphi consultative approach to develop consensus around specific elements of the programme theory, informed by the findings from WP2 – and hence to agree appropriate fidelity criteria and relevant outcome measures that can be used in the ongoing roll-out of FGC in adults social care and mental health. The Delphi exercise would be inclusive, involving people with experience of FGCs alongside practitioners, service managers and other stakeholders, and would be hosted by Community Catalysts. People will be invited to take part in the consultation via advertisement on the FGC Adults Research and Practice Network.

The process will be conducted online with a final face-to-face confirmatory event. The definitive Programme Theory and consensus-based fidelity criteria will then be translated into standards and guidance for FGC practice.

## 6. Study setting

FGC services for adults and mental health typically operate within statutory service provision (local authority or NHS Trust) with co-ordinators either being employed as a separate team within the statutory service, or as external contractors recruited from a bank of trained staff. Typically they will operate from separate community premises that are informal and are away from other Council offices, NHS services or care provision. These settings will however offer confidential spaces in which research interviews and observations can be undertaken. Alternatively, according to people’s preferences, interviews may take place at their homes (in accordance with University of Birmingham lone working policy) or at the office base for the FGC service in local authority or NHS Trust premises.

The selection of potential sites is pragmatic, given the relatively low level of current activity in adult social care and mental health. The sites chosen will be ones where there is an established FGC service for adults and/or mental health (where the model is properly bedded in) and where the referral rate is sufficient in order to facilitate recruitment of our target numbers within a 6 months recruitment window. It is intended that sites will offer some diversity in organisational and geographical context (size of local authority / NHS Trust), and that more than one site will have substantial representation of minority communities.

Based on detailed enquiries through Principal Social Worker and other professional networks, there are only 3 sites nationally that would appear currently to meet the above criteria. Therefore, provisionally, the chosen sites will be Essex, Camden and Birmingham.

However, this will be reviewed with the Study Steering Group prior to commencement of fieldwork, with the possible substitution or addition of alternative sites if appropriate.

The FGC service in Essex is a separately managed unit within a partnership NHS Trust that delivers mental health services including social care. It has a mixed urban and rural catchment. The FGC service in Camden is generic across adult social care and co-ordinators are drawn from a pool of externally contracted trained Co-ordinators. Both the Camden and Essex services have been established and running for some years. The Birmingham service is more recent, being established for around 2 years. It is a separately managed in-house team taking referrals from across the local authority's adult social care services. There is substantial ethnic and cultural diversity within Camden and Birmingham (less so in Essex) and this is reflected in the composition of those available as co-ordinators.

## 7. Participant recruitment and sampling

*Staff and stakeholders eligibility criteria*

For each service participating in the study, we will seek to interview the FGC Service Manager, Principal Social Worker (or equivalent) and other relevant managers/commissioners as identified by the site lead in the local authority / NHS Trust.

For each family/network included in the FGC and Non-Conference samples we will seek to interview the FGC Coordinator

*Individuals and family/network members*

From each service, we will recruit samples of individuals and one or more of their family/network members as detailed below. A stratified sampling strategy using pre-specified target quotas will be used to ensure, as far as is possible, good representation of different service user groups and of people from minority communities within the FGC Sample. The theoretical rationale for this is to maximise our ability, within the overall number of case studies, to identify whether there are some service user groups or communities for whom FGC may offer a better or worse 'fit' in terms of process and/or outcomes.

To exclude any inadvertent focus on 'success stories' in the selection process, (a) recruitment will be at the point that people are accepted for a FGC service, and (b) the FGC sample will be recruited sequentially – i.e, first x individuals and their family/networks that come into the FGC service from the start of the 6 month recruitment 'window' who meet the criteria for each of the target quotas detailed below (and who consent to take part in the research). Recruitment will pause for each quota once the target number proceeding to full Conference is achieved. Recruitment across the 3 sites will be reviewed at 4 months, with the possibility of allowing over-recruitment on particular sites to compensate for under recruitment elsewhere. People who do not proceed to a full Conference, will be transferred to the Non-Conference Sample (see below) until target numbers have been reached.

**FGC Sample**: from across the sites, a total of 25-30 family/network case studies that went through to a full Conference with follow-up 9-12 months after the Conference to assess whether any positive changes are sustained. By setting and reviewing target quotas for each site, we will aim, across the sites, for a minimum of 8 family case studies each for:

mental health; older adults; and adults with, and for a minimum of 25% of the overall sample to be from BAME backgrounds.

**Non-Conference Sample**: from across the sites, a total of 12-15 family/network case studies which did not carry through to a full Conference (for whatever reason) – again with follow-up at 9-12 months.

**Comparator Sample for cost / consequence evaluation:** from each site we will recruit a 1:1 matched comparator sample of people and family/network members who will be receiving a similar social care or mental health ‘service as usual’ as those included in the FGC Sample: 25-30 in total. Matched comparators will be selected on the basis that they are (a) from the same service user group (e.g. older people, physical disability etc), (b) have identified family or other support network and would have met the acceptance criteria for the FGC service and (c) have similar demographic characteristics (age group, gender, BAME / non-BAME). The comparator sample will also be followed up at 9-12 months.

***Inclusion criteria***

Any adult (18 and over) with identified social care or mental health needs who has been referred to a Family and Group Conferencing service and one or more of their family/network members.

These will then fall into 2 samples of interest:

(a) Those that go on to take part in a Conference (FGC sample)

(b) Those that, for whatever reason, do not proceed to a Conference (Non-Conference sample)

Comparator group: from each site we will recruit a 1:1 matched comparator sample of people and family/network members who will be receiving a similar social care or mental health ‘service as usual’ as those included in the FGC Sample. Matched comparators will be selected on the basis that they are (a) from the same service user group (e.g. older people, physical disability etc), (b) have identified family or other support network and would have met the acceptance criteria for the FGC service and (c) have similar demographic characteristics (age group, gender, BAME /non-BAME).

We will also seek to maximise ethnic and cultural diversity within the overall sample. Two of the proposed sites (Camden and Birmingham) have particular ethnic and cultural diversity within their populations and it is from these sites where we will hope to recruit more individuals and families from diverse backgrounds. Initial scoping demonstrates that these FGC services attract a substantial proportion of families from such backgrounds – and this is aided by the diversity of background among FGC coordinators. Provision has been made in the budget for interpreters and translation costs where interviewees may not be sufficiently fluent in English.

It is also important to emphasise that FGC services are inclusive of all potential configurations of family, friends and significant others – so no-one will be excluded from the sample on the basis of sexual orientation or non-normative family arrangements.

In addition, we will recruit a comparator sample as defined above.

***Exclusion criteria***

Individuals or family/network members lacking mental capacity, or where services have concerns that participation in the research could adversely affect their wellbeing. It will be for the service to make professional judgements as to concerns around whether any potential participant would have capacity to consent to take part in the research and/or whether there are other circumstances which would indicate that participation in the research might adversely affect their wellbeing.

### *Recruitment and information materials*

Recruitment will be overseen by the site lead based within the local authority or NHS Trust.

Until we have recruited to the sample as specified above, we will ask that all new families accepted in a six month period are automatically approached by the FGC Team in the local authority or NHS Trust to see if they wish to consider participating in the research. Potential participants (individual and participating family/network members) will be given a flyer giving an easy-read brief description of the research and what would be asked of them. This flyer can be translated into relevant community languages as necessary. If people are interested, their contact details will be forwarded to the Research Team who will then provide a more detailed Participant Information Sheet and Consent Form (with easy read versions or translations if preferred by potential participants), including details as to how data will be stored (see Section 9). Members of the Research Team will be available to answer questions about the research.

### *Consent*

#### *Staff and stakeholders*

Initial contact with staff and stakeholders will be made via the agency-based site lead who will seek their permission for the Research Team to provide them with information on the research and consent forms. They will record consent to contact. Written consent (via email or hard copy) will be obtained before the start of interviews.

#### *Individuals and family members*

If people indicate to the staff member that they may interested, their contact details will be forwarded to the Research Team who will then make contact with them in order to provide a more detailed Participant Information Sheet and Consent Form (with easy read versions or translations as appropriate), including details as to how data will be stored, and to answer any questions about the research. If necessary, an interpreter will be provided. Consent to contact will be recorded on the case record held by the local authority / NHS Trust

On the Consent Form, participants will have the option to select whether or not they will allow a member of the research team to observe the process of the Conference.

Written consent will be taken either by a member of the research team or by a member of research support staff within the agency / Clinical Research Network who has appropriate training and experience in taking consent. Consent will either be taken face to face or following a discussion online or by telephone to check that the person has full understanding and is able to give informed consent. The signed consent form may then either be posted in hard copy (in Stamped Addressed Envelope provided) or attached via email.

### *Payments and rewards*

In recognition of the level of involvement required, and the wish to track progress over a 9 month period, families in each sample will be offered reward in the form of shopping vouchers on a staged basis.

### *Participant support and drop-out*

Participants will normally be followed through by the same researcher(s) with whom it is hoped that rapport may be established – and who therefore can be available for support, if required, in addressing any concerns that may emerge during the course of the research. In many instances, this will be a researcher with a lived experience background – which may make it easier for participants to ask for and receive support that is relevant to their needs.

It is possible that some families may move on or move away during the study period. It is hoped that the offer of recognition and reward may encourage participants to stay in touch so as to receive follow-up questionnaires.

In the event of a participant requesting that they withdraw, they can ask for any data collected in the previous 7 days to be deleted. Otherwise, data obtained so far will be retained.

## 8. Safety reporting

Not relevant in this study as no medical procedures or treatments

## 9. Ethical and regulatory considerations

### *Assessment of risk and safeguarding*

In the event of a research participant disclosing a significant risk to self or others, information would immediately be passed to relevant authorities in the local authority / NHS Trust providing services to the participant.

### *Research Ethics Committee (REC) and other Regulatory review & reports*

Ethical approval for the scoping survey and follow-up interviews in WP1 has been obtained from the University of Birmingham, as this element of the research does not meet the criteria for research activity that requires NHS REC approval. WP3 comprises a consultation exercise and does not involve data gathering – and so ethical permission is not required.

Before commencing field research for WP2, a favourable opinion will be sought from an NHS Research Ethics Committee tagged for social care research. In addition:

- Substantial amendments that require review by NHS REC will not be implemented until that review is in place and other mechanisms are in place to implement at site.
- All correspondence with the REC will be retained.
- It is the Chief Investigator’s responsibility to produce the annual reports as required.
- The Chief Investigator will notify the REC and sponsor of the end of the study.
- An annual progress report (APR) will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.
- If the study is ended prematurely, the Chief Investigator will notify the REC and sponsor, including the reasons for the premature termination.
- Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the REC and sponsor.

### *Regulatory Review & Compliance*

Before any site can recruit participants into the study, the Chief Investigator or designee will ensure that appropriate approvals from participating organisations are in place.

### *Amendments to protocol*

Any proposed amendment to the protocol will need to be approved by the Study Steering Committee before it is submitted to the sponsor who will decide whether an amendment is substantial or non-substantial.

In accordance with the guidance in the help section in the Integrated Research Application System (IRAS) any amendments will be notified to appropriate review bodies.

### *Peer review*

The research proposal was subject to independent peer review when application was made to the national Institute for Health and Care Research.

### *Patient & Public Involvement*

People with lived experience of social care and health services, including those who have participated in FGC, have been involved in the development of the proposal. They see the coproductive design of the WorkPackages, and the integral role of lived experience researchers, as fitting well with the ethos of FGC. Two lived experience researchers will have key ongoing roles as Co-investigator or Collaborator – and there is provision in the budget for additional people with lived experience to be recruited as co-researchers for each research site.

Clenton Farquharson MBE, who has lived experience of disability and mental health services and is Co-chair of Think Local Act Personal, is lead for PPI. He will facilitate a Lived Experience Advisory Panel comprising two representatives with experience of FGC from each of the research sites. This Panel will meet regularly with the Research Team and support the involvement of people with relevant lived experience in consultative and knowledge exchange events.

### *Protocol compliance*

Any deviation for the Protocol will be reported to the Study Steering Committee and action agreed to prevent likelihood of recurrence.

### *Data protection and patient confidentiality*

All investigators and study site staff will comply with the requirements of the Data Protection Act 2018with regards to the collection, storage, processing and disclosure of personal information. All personal data collected during the course of the study will be kept strictly confidential. Names and contact details of participants will be stored separately from other data and participants will be given codes for pseudononymisation.

All data will be pseudononymised and codes used in lieu of personal details. The password and the codes for pseudononymising the data will be kept in a separate location on the University server. No one other than the research team will have access to the data unless there is a complaint about the research (in which case, it may be inspected by relevant regulatory authorities). No identifying personal information will be included in interview transcripts, questionnaires or other stored data.

Audio recordings of interviews will be undertaken on encrypted devices and transferred to secure University of Birmingham Research Data Storage after which the recording will be deleted from the recording device. Telephone or online interviews will be recorded on an encrypted device positioned next to the telephone or computer. Online interviews will be made on University Zoom/Teams accounts. Audio recordings will be sent securely to a transcription company with which the University has a contract and confidentiality agreement in place. Transcripts will be redacted for any personally identifying material by a member of the research team before being stored in secure University of Birmingham Research Data Storage. Recordings will be deleted after transcription. Family Group Conferences will not be audio recorded.

All data on paper will be stored in locked filing cabinets accessible only to members of the research team.. All electronic data will be stored on University of Birmingham storage (BEAR Research Data Store), accessed via network shares mounted on the computers of the Principal Investigator, Co-investigators and other researchers. Access to the data is restricted to those who have been granted access to the project by the Principal Investigator. Data can only be accessed off campus through use of the 2-factor authentication remote access service (VPN). External members of the research team will be able to share research data via a secure Teams site which can then be uploaded on BEAR.

### *Indemnity*

The University has in force a Public Liability Policy and/or Clinical Trials policy which provides cover for claims for "negligent harm" and the activities here are included within that coverage.

### *End of study*

The end of the study will be defined as 12 months after completion of the funded research (July 31st 2015) to allow for submission and revision of publications.

### *Archiving and access to the final study data set*

Research data will be archived securely for 10 years after the publication of all peer-reviewed Papers, in line with the University of Birmingham Research Data Management Policy, and will only be accessible upon an application for restoration by an appropriate person such as the Principal Investigator or an authorised member of the research team. The data will then be disposed of, including deletion from storage servers and backup tapes.

## 10 Dissemination strategy

***WP4: Knowledge Exchange and Impact*** (Objective vii; 3-33 months) – see below Objective (vi) (0–36 months) Co-leads: Jerry Tew, Tim Fisher in conjunction with Community Catalysts.

Building on the existing Practice Network for adults' FGC coordinated by Fisher, we will facilitate a FGC Research and Practice Network for knowledge exchange and practice development. It will be hosted by Community Catalysts CIC – a national organisation which already supports research and implementation in relation to other asset-based approaches such as Local Area Coordination.

We will provide attend or provide briefings to the regular national meetings of the Principal Social Worker Network that is convened by the Chief Social Worker for Adults.

The Network will promote a series of events throughout the research project - feeding into the research process via involvement in WP1 and WP4 as well as being a vehicle for the dissemination and application of findings. A Network Website will host information on forthcoming events and consultations – together with news sheets, project outputs and FGC resources and training materials. We will work with the Network throughout to consider issues of implementation of the emerging model of FGC and, hence, to inform the detail of the outputs of this project to ensure they are directly relevant to practice with clear guidance to real-world implementation.

The specific outputs from the Project will include:

- Website hosting project outputs and FGC resources, tools and contacts
- Six-monthly news-sheet with updates of progress
- A minimum of 4 Working Papers for the Practice and Research Network and Website
- Submission of 2-3 Papers for peer review and Open Access publication via NIHR Open Research or relevant Journals
- An e-learning package of video and other online resources for organisations who are already offering, or looking to set up, FGC services. This will be developed by *Research in Practice* and the resources would be available free of charge. It will comprise modules on:
  - What would you say to families thinking of becoming involved in a family group conference?
  - A guide to setting up an adults' FGC service
  - Sharing power, advocacy and supporting decision making – principles and practicalities
  - What does best practice look like in preparing for a conference?
  - What does best practice look like in supporting families to implement and review their plans?
- Final Report linking publications and outputs together
- National knowledge exchange event in conjunction with the organisations and networks listed above

### *Authorship eligibility guidelines*

All publications and reports will name as authors only those members of the research team who have actively contributed to the analysis and writing the particular publication. The Final Report will credit all members of the research team. There will be no use of professional writers.

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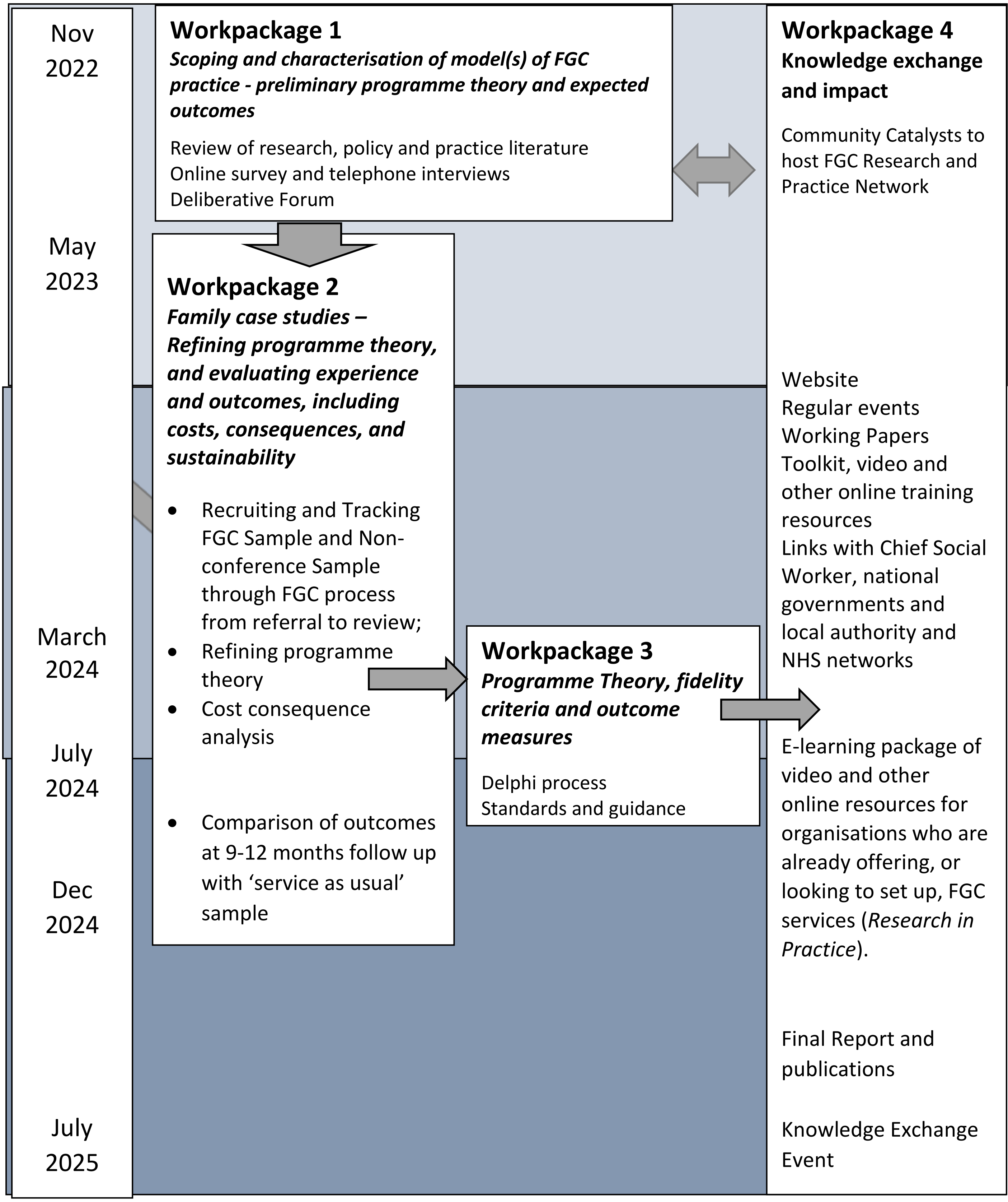
## 12 Study flowchart



Nov 2022

May 2023

March 2024

July 2024

Dec 2024

July 2025

**Workpackage 1**

***Scoping and characterisation of model(s) of FGC practice - preliminary programme theory and expected outcomes***

Review of research, policy and practice literature
Online survey and telephone interviews
Deliberative Forum

**Workpackage 2**

***Family case studies – Refining programme theory, and evaluating experience and outcomes, including costs, consequences, and sustainability***

- Recruiting and Tracking FGC Sample and Non-conference Sample through FGC process from referral to review;
- Refining programme theory
- Cost consequence analysis
- Comparison of outcomes at 9-12 months follow up with 'service as usual' sample

**Workpackage 3**

***Programme Theory, fidelity criteria and outcome measures***

Delphi process
Standards and guidance

**Workpackage 4**

**Knowledge exchange and impact**

Community Catalysts to host FGC Research and Practice Network

Website
Regular events
Working Papers
Toolkit, video and other online training resources
Links with Chief Social Worker, national governments and local authority and NHS networks

E-learning package of video and other online resources for organisations who are already offering, or looking to set up, FGC services (*Research in Practice*).

Final Report and publications

Knowledge Exchange Event