Codesigning a social prescribing pathway to address the social determinant of health concerns of children with cerebral palsy and their families in Australia: a protocol for a mixed-methods formative research study

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ABSTRACT

Introduction Social determinants of health (SDH) are contributors to health inequities experienced by some children with cerebral palsy and pose barriers to families engaging with complex and fragmented healthcare systems. There is emerging evidence to support ‘social prescribing’ interventions that systematically identify SDH concerns and refer patients to non-medical social care support and services to address their needs. To date, social prescribing has not been trialled specifically for children with neurodevelopmental disabilities, including cerebral palsy, in Australia. This study aims to codesign a social prescribing programme to address SDH concerns of children with cerebral palsy and their families who attend one of the three tertiary paediatric rehabilitation services in New South Wales, Australia.

Methods and analysis This is a qualitative multi-site study conducted at the three NSW paediatric hospitals’ rehabilitation departments using a codesign approach. Children aged 12–18 years with cerebral palsy, parents/caregivers of children (aged 0–18 years) with cerebral palsy, and clinicians will be involved in all stages to codesign the social prescribing programme. The study will consist of three components: (1) ‘what we need’, (2) ‘creating the pathways’ and (3) ‘finalising and sign off’. This project is overseen by two advisory groups: one group of parents of young people with cerebral palsy, and clinicians will be involved in all stages to codesign the social prescribing programme. The study protocol was approved by the human research ethics committee of the Sydney Children’s Hospitals Network. This codesign study will inform a pilot study of feasibility and acceptability, then if indicated, a pilot clinical trial of efficacy. We will collaborate with all project stakeholders to disseminate findings and undertake further research to build sustainable and scalable models of care.

Trial registration number ACTRN12622001459718.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This is a mixed-methods research study using codesign research practices.
⇒ Participants include young people with cerebral palsy, parents/caregivers of young people with cerebral palsy, and clinicians working with children with cerebral palsy.
⇒ A strength of this study is the involvement of research advisors with a lived experience of cerebral palsy to ensure community priorities are central to research design and conduct.

INTRODUCTION

Cerebral palsy is a lifelong condition and the most common cause of physical disability in childhood. In Australia, the birth prevalence of cerebral palsy has recently declined to 1.2 per 1000 live births.12 Cerebral palsy describes a heterogeneous group of permanent but not changing disorders of movement and/or posture caused by a non-progressive lesion or anomaly to the immature brain.5 Among
individuals with cerebral palsy, the motor subtypes are clinically described as spastic, dyskinetic, ataxic, or hypotonic, and the functional limitations range from minimal to severe.¹ Many children and young people (henceforth described as ‘children’) with cerebral palsy are ambulant (≥60%) and do not have comorbid health concerns. However, some children experience comorbidities that can further complicate their health, including epilepsy (≥30%), and difficulties with their vision (≥35%), hearing (≥10%), speech (≥60%) and intellectual disability (≥15%).¹³

Thus, children with cerebral palsy often have greater health and social needs, and service demands than their peers without cerebral palsy.⁴ ⁵ This includes frequent and repeated interaction with services including tertiary specialised healthcare services and community-based therapy. Best practice involves a multidisciplinary team framework guided by the International Classification of Functioning, Health and Disability model.⁶ This biopsychosocial conceptualisation of health and disability makes the goal of clinical intervention to optimise individual functioning (body structures, body functioning, activities and participation) within the individual’s personal and community context.⁶ These contextual factors (personal and environment) include the social determinants of health (SDH).

**Impact of SDH for children with cerebral palsy**

There is clear evidence that there are health inequities which are the ‘unfair, unnecessary, avoidable and systematic differences in health status’⁷ in the severity of cerebral palsy. Canadian and Australian studies have shown that children with cerebral palsy born in more affluent neighbourhoods are more likely to be ambulant compared with those born in more disadvantaged neighbourhoods.⁸ ⁹ Adolescent motherhood and maternal minority ethnicity are also associated with more severe impact on gross motor function in children with cerebral palsy.⁸ There are also clear inequities in access to healthcare services. In Australia, socioeconomic disadvantage is significantly associated with non-attendance of outpatient clinics for children with cerebral palsy, highlighting a critical barrier to healthcare accessibility.¹⁰ This is an example of the ‘inverse care law’, where ‘the availability of good medical or social care tends to vary inversely with the need of the population served’.¹¹

These inequities have their origins in the SDH, which are ‘the non-medical factors that influence health outcomes’.⁷ They are ‘the conditions in which people are born, grow, work, live, and age’, including education, housing, transportation, food security and employment.⁷ SDH can be protective factors to support optimal health outcomes (eg, safe housing and accessible transport or) risk factors for adverse health outcomes (eg, food insecurity and financial hardship), including access in already complex and fragmented healthcare systems. For many families of children with cerebral palsy and other neurodevelopmental disabilities, the burden of SDH concerns has worsened with the COVID-19 pandemic.¹²

**Interventions to address social determinants of health concerns: a case for social prescribing**

There is emerging evidence that families SDH concerns can be effectively addressed by training clinicians to identify these in a respectful way and supporting families by linking them with local non-governmental organisations and community services.¹³ Studies in the USA have identified that these schemes are both feasible and acceptable to families.¹⁴ ¹⁵ Families receiving these interventions are up to 44 times more likely to obtain assistance within 4 months of the SDH concern being identified,¹⁶ ¹⁷ and these interventions result in significant family-reported improvements in child health.¹⁸ In the primary care setting of the UK, ‘social prescribing’ is emerging as a formalised scheme for service providers to identify and refer patients to non-medical community services to address their SDH concerns.¹⁹ In practice, a ‘link worker’ supports patients to access locally available services that match their needs and preferences.¹⁸ Social prescribing schemes for young people are developing in the UK¹⁹ but have not been applied specifically for children with cerebral palsy or other complex chronic medical conditions.²⁰

The Royal Australasian College of Physicians and the Royal Australian College of General Practitioners and Consumers Health Forum of Australia Report recognised that Australian families may benefit from social prescribing, particularly those with chronic physical health conditions and multimorbidity.²¹ ²² To date, social prescribing has not been trialled for children with neurodevelopmental disability, including cerebral palsy, in the Australian context. This study aims to address this critical research gap.

**Aims and objectives**

The Equity Pathways and Integrated Care in Cerebral Palsy (EPIC-CP) project aims to codesign a social prescribing programme to address the SDH concerns of children with cerebral palsy and their families who attend the three tertiary paediatric rehabilitation services in NSW.

Once codesigned, our ultimate aim is to support clinicians to identify children with cerebral palsy (aged 0–18 years) and their families who are experiencing SDH concerns in their clinics and to link them through the social prescribing programme to the services they need, resulting in addressing their SDH concerns, improving child well-being, parental mental health, and family functioning.

Codesign research is defined as ‘meaningful end-user engagement in research design and includes instances of engagement that occur across all stages of the research process’.²³ Using codesign can ensure the planning and implementation of an intervention address the areas of need from the perspective of service users and is an effective approach for engaging marginalised patient
In this project, research end users include children with cerebral palsy, parents/caregivers of a child/young person with CP, clinicians, research academics, and stakeholders from health services and non-governmental organisations.

METHODS
Study design
This is a mixed-methods study using codesign approach, guided by the Hawkins et al. framework for intervention coproduction and prototyping, and principles of participatory action research with key stakeholders at the centre of the research process. The study commenced in August 2021 and the planned end date is December 2022. This study has three components (figure 1).

Component 1: ‘what we need’
Qualitative methods (interviews, focus groups, and arts-based methods) will be used to explore the experiences of children with cerebral palsy and their families facing SDH concerns, the current enablers and barriers for families to address these concerns, and what is needed from the future social prescribing programme. These perspectives will be sought from children with cerebral palsy (aged 12–18 years), parents/caregivers of children (aged 0–18 years) with cerebral palsy, and clinicians working with children with cerebral palsy and their families.

One-on-one semistructured interviews will be conducted with children with cerebral palsy and parents/caregivers. The semistructured interview guide will first be piloted with the project research advisors. Then, together with research advisors, the guide will be adapted to ensure the interview questions are suitable and the language is appropriate for children with cerebral palsy and parents/caregivers (table 1). A Photosymbols booklet developed by the research investigators and research advisors will be used during interviews with children to assist discussions and support participants to share their first-person insights. Focus groups (5–10 participants) will be conducted with clinicians across the three study sites. Interviews and focus groups will take approximately 1.0–1.5 hours, with the duration being flexible based on participants preferences and accounting for management of participant fatigue.

We recognise that approximately 25% of children with cerebral palsy have complex communication (access) needs. As an alternative qualitative approach, arts-based methods (photovoice and body mapping) will be conducted with children who are not able to participate in semistructured interviews. These methods have been successfully used with people with intellectual disability and autism spectrum disorder. Two sessions (approximately 1 hour each) will be conducted separately with the participant. The first session will aim to build rapport, explain the process of photovoice/body mapping, and start the exemplar photos discussion/creation of the body map. The second session will discuss the photos selected by participants/finish the body map, with an opportunity for the participant to explain their photos/body map and to ask any further relevant questions from the interview schedule that were not covered during the body mapping process.)

Figure 1 Framework for phase I formative design of EPIC-CP research project based on Hawkins et al.26 EPIC-CP, Equity Pathways and Integrated Care in Cerebral Palsy; RCT, randomised controlled trial; SDH, social determinant of health.
Location and time for the qualitative data collection will be negotiated with the participants prior to data collection. This will be conducted online via videoconferencing or face-to-face, depending on participant personal preference and public health orders in place due to the COVID-19 pandemic.

Component 2: ‘creating the pathway’

Component 2 will involve a series of workshops across the study sites. Key findings from component 1 will be fed back to participants through presentation of a qualitative needs assessment, with review and reflection of ‘what is needed’ to inform the subsequent ‘creating the social prescribing pathway’. Then, in a series of three to five workshops and action research cycles, the participants will together cocreate a logic model to inform the social prescribing programme and a prototype for social prescribing programme.

During these action research cycles, participants will consider the existing literature, the findings from the qualitative needs assessment, and their own lived experiences and expertise. Ideas will be presented to participants by the project officer, feedback on ideas sought, revisions made and presented again, until final content is agreed on.

To minimise potential power imbalances, workshops will be conducted separately as (1) children and parent/carer participants and (2) clinician participants. Furthermore, a series of clinician workshops will take place at each rehabilitation department site to gain local context for each site. Clinicians will use iterative action feedback cycles to pilot and refine key components of the pathway with a small group of children with cerebral palsy and their families attending the rehabilitation department cerebral palsy clinics over a period of 1–2 months. This will allow the investigator team to refine the intervention and feedback clinicians’ experience of using the pathway in routine clinical practice into component 3 of the study design. Each workshop will last 1–2 hours and will take place face-to-face or virtually dependent on participant personal preference and/or public health orders in place due to the COVID-19 pandemic.

Component 3: ‘finalising and sign off’

During component 3, the final draft of the logic model and social prescribing programme, including the clinical pathway and its core components, standard operating procedures for the community link worker, a position description and associated referral resources, will undergo expert review by the research investigators, steering committee, knowledge translation committee and research advisory groups. Resources will then be presented and reviewed with children with cerebral palsy, parents/caregivers, and clinicians at each study site through finalisation workshops with a focus on consensus building. On receiving sign-off from participants and stakeholders, the final pathway will then be written up into a manualised form for the next phase of the study: a pilot feasibility randomised controlled trial (RCT).

Study setting

New South Wales (NSW) is the most populous state in Australia with over 8.1 million people residing across metropolitan, rural, and remote regions. The three publicly funded tertiary paediatric hospitals in NSW are Sydney Children’s Hospital Randwick, the Children’s Hospital at Westmead, and John Hunter Children’s Hospital. Each paediatric hospital has a rehabilitation

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<th>Table 1</th>
<th>Semistructured interview/focus group questions adapted and finalised based on feedback from EPIC Advisory Groups</th>
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<td><strong>Semistructured interview questions for children with cerebral palsy</strong></td>
<td><strong>Semistructured interview questions for parents/caregivers</strong></td>
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<td>How do these everyday things in life (show Photosymbols booklet of SDH) affect you, your family, and people in your life? Which of these everyday things (SDH) affect your life the most? Who or what helps you and your family when you need support with these everyday things in life (SDH)? For example, this might be a family member, friend, doctor, disability support worker or a service (eg, National Disability Insurance Scheme). How do these people or services help you? What makes it hard to get the help you and your family need for these everyday things? What would help you and your family with these everyday things?</td>
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EPIC, Equity Pathways and Integrated Care; SDH, social determinant of health.
department where multidisciplinary clinical services are provided for children with cerebral palsy.

**Study participants**

Eligible participants are

- Children with cerebral palsy aged 12–18 years attending one of the three NSW paediatic hospital rehabilitation departments.
- Parents/caregivers of a child/young person (aged 0–18 years) with cerebral palsy attending one of the three NSW paediatric hospital rehabilitation departments.
- Clinicians working in one of the three NSW paediatric hospital rehabilitation departments.

**Recruitment**

The project will be promoted through the three rehabilitation departments, Cerebral Palsy Alliance (CPA), and the NSW/Australian Capital Territory (ACT) Cerebral Palsy Registers using approved study resources (information flyer, short information video and participant information sheets) (figure 2).

Approved recruitment resources will be displayed in the rehabilitation departments’ waiting rooms, and clinicians will provide these resources to children with cerebral palsy and parents/caregivers during their routine clinical care. If children and parents/caregivers are interested in participating and consent to being contacted, the project officer, who is not involved in the child/young person’s care, will contact the family directly. The project officer will explain the study in further detail and answer any questions prior to seeking informed consent for study participation. Study advertisements will be included in the NSW/ACT Cerebral Palsy Register newsletter, and recruitment emails will be distributed to families included on this register who have elected to receive research invitations. Study personnel details will be included and interested families may contact the project officer directly if they are interested in taking part.

Clinicians will be identified via department meetings and networks, before being approached by the project officer. They will be provided with participant information sheets and consent forms (PISCFs), will be given

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Figure 2  Flowchart of recruitment processes. ACT, Australian Capital Territory; NSW, New South Wales.
time to consider participating and can ask any questions before providing information written consent.

Sample size
As this is inductive rather than deductive research, a predetermined sample size cannot be calculated. However, we estimate that during component 1, we will interview approximately 10–15 children with cerebral palsy, 10–15 parents/caregivers, and 10–20 clinicians. Similarly, approximately 10 children with cerebral palsy, 10 parents/caregivers, and 15 clinicians will participate in components 2 and 3. The proposed sample size is similar to approaches used in other mixed-methods research for programme codevelopment in children with neurodevelopmental disabilities (including cerebral palsy). It is acknowledged that some parent/caregiver participants may have a relationship with child participants, and this may introduce bias in the sampling. Nonetheless, these participants will remain eligible to take part in the study as the lived experience of SDH concerns is individualistic and may differ between children and their parent/caregiver.

This qualitative study will use purposive sampling. This includes approaching families from different cultural, linguistic, and socioeconomic backgrounds; those who have expressed concern about meeting their SDH concerns and those who have not, and families of children with cerebral palsy with a wide range of clinical phenotypes. Additionally, snowballing will also be used to identify participants (i.e., word of mouth) and convenience sampling. Saturation point will be determined to have been reached when there are no new themes emerging and ‘negative’ cases for each emerging theme have been identified.

Informed consent
PISCFs will be developed specifically for children with cerebral palsy, parents/caregivers, and clinicians. Separate PISCFs will be provided for each study component. Participants may take part in one or multiple components of the study.

Children will be provided PISCFs in Easy Read English format and a verbal explanation of the study by the project officer at the time of recruitment. The information sheets will be used as an aid but will not be the sole method for communicating details of the study and obtaining informed consent. Additional time will be allowed for communicating details of the study and obtaining consent in a way that is best suited to participants. The project officer will schedule a discussion with children prior to the interviews and focus groups to discuss the semi-structured interviews and workshop agendas, and to understand any accommodations required for their preferred methods of communication and participation.

Written and signed consent will be obtained from each study participant. A parent/caregiver’s PISCF will be also obtained for every child under 18 years of age. Participants will be assured of confidentiality and anonymity as data will be stored in a deidentified manner in a safe and secure environment. All participation in the study will be voluntary. Participants will be assured that they can stop participating at any time, without any consequences to them or any health services they are receiving.

Data collection
All participants will be allocated a unique identifier code that will be used throughout the course of the project. All paper copy and taped data will be deidentified. Coded information will be stored in a locked filing cabinet or on password-protected digital media. Interviews/focus groups will be carried out by the project officer with support from other members of the investigator team as required. Comments made during the focus groups/workshops will be heard by other participants, and therefore confidentiality of comments will not be guaranteed. Nonetheless, individual comments will be stored and analysed confidentially by the research team.

Narrative data will be collected through field notes and audio recordings of interviews/focus groups. Interviews/focus groups will be transcribed verbatim, and all data management, storage and analysis will be performed at the Population Child Health Group, University of New South Wales (UNSW). As soon as interviews/focus groups have been transcribed, the audio recording will be erased. Field notes will be scanned and stored electronically, and hard copies will be destroyed after 15 years. Any electronic data will be kept on a password-protected computer at the Population Child Health Group, UNSW. The project officer and principal investigator will have access to the stored and locked data. All personal information collected about the participants will be protected under current NSW privacy legislation. Any person with access to personal information collected as part of the study will be bound by a duty of confidentiality.

Data analysis
The overarching theoretical framework guiding this qualitative study is the biopsychosocial ecological framework. Furthermore, the Hawkins framework for coproduction will guide components 2 and 3. This approach will be used with all study participants: children with cerebral palsy, parent/caregivers, and clinicians.

Interviews/focus groups/workshops will be digitally audio-recorded, transcribed verbatim, and thematically analysed to identify, interpret, and report on the repeated patterns of meaning within the data, drawing from Braun and Clark et al’s thematic analysis approach. Data collection and analysis will continue until a ‘saturation point’ is reached; that is, no new themes or hypotheses emerge. The visual data (photos and body maps) will also be analysed using thematic analysis.

Where appropriate, NVivo software will aid in the coding and organisation of themes. Researcher triangulation will be employed to further substantiate the emerging themes with all project team members (including research advisory groups) as this represents a wide range
of backgrounds and perspectives in the field of neurodevelopmental disability and equity research.

**Working with Aboriginal and Torres Strait Islander people to codesign a culturally safe social prescribing pathway**

The EPIC-CP team recognises that Aboriginal and Torres Strait Islander people continue to experience health and disability inequities as a result of the ongoing effects of colonisation. Aboriginal and Torres Strait Islander children with cerebral palsy living in NSW may access rehabilitation services across the three sites. They will be included in the overarching EPIC-CP research project and the codesign of a social prescribing pathway. In addition, Aboriginal and Torres Strait Islander people will codesign a culturally safe social prescribing pathway for Indigenous Australians. This work will be led by Aboriginal researchers and health service managers (TM and MS).

Aboriginal and Torres Strait Islander children and their parents/caregivers will be recruited by using purposive sampling from John Hunter Children’s Hospital and Awabakal Aboriginal Medical Service after consultation with these services. Yarning circles will be conducted face-to-face following the ancient concept of sitting together in a circle and telling ‘yarns’ while practically using your hands and interacting. Yarning circles will be conducted with Indigenous art-based group activities (eg, weaving and painting) to create a non-threatening and safe environment for participants. They will be conducted at a location that is suitable for the participants using a yarning guide. The yarning questions will be developed by investigators TM, MS, and the EPIC-CP team in consultation with these services and the CPA Community, Aboriginal and Torres Strait Islander Reference Group (CARG). The yarning circles will continue until data saturation is achieved and will be audio-recorded and transcribed verbatim. Using NVivo software, investigators TM, MS, and the EPIC-CP team will conduct a qualitative analysis. The analytical framework will be discussed with CPA CARG to ensure that our current conceptual frameworks adequately capture the scope of the data. Key themes will be fed back to the participants for their reflections on it. An ethics application will be submitted to the Aboriginal Health and Medical Research Council.

**Patient and public involvement**

Per our codesign approach, children with cerebral palsy, parents/caregivers, and clinicians will be involved in all phases of the research project. People with a lived experience of cerebral palsy were involved in the consultation process for the development of the initial project proposal, development of ethics protocol, and this protocol manuscript. Each child with cerebral palsy and parent/caregiver will be paid $A30 per interview or workshop.

The EPIC-CP project has a governance structure incorporating several subcommittees (figure 3). Each committee meets regularly with the chief investigator, project officer and relevant members of the investigator team to ensure effective communication and collaboration between all stakeholders (young adults with cerebral palsy, parents/caregivers, clinicians, research investigators and key stakeholders from health service delivery sectors, policy makers and non-governmental community organisations).

This project is overseen by two advisory groups: one group of young adults with cerebral palsy (eight members) and one group of parents of a child or young person with cerebral palsy (six members). The advisory groups have input into each phase of the study, including development of the semistructured interview schedule.
commenting on the qualitative findings, developing the pathway, and knowledge translation strategy. They are invited to meet with the project officer monthly and are paid $A30 per hour.

ETHICS AND DISSEMINATION

Ethics and considerations

Ethics approval for this project was granted by the Sydney Children’s Hospitals Network (SCHN) Human Research Ethics Committee (2020/ETH01376) in September 2020. Site-specific research governance approvals were granted for SCHN and John Hunter Children’s Hospitals. An NSW Health Aboriginal Health Impact Statement was completed for this project.

Potential harm related to this qualitative research is related to the power relationship between research investigators and the participants. The most obvious power discrepancy in this study relates to principal and coinvestigators who are health professionals at the study sites and may be involved in the medical care of children with cerebral palsy participating in the research. To minimise the potential power imbalance, the project officer who is not involved in any clinical care will be responsible for qualitative data collection with children and parents/caregivers.

This project may identify families where there is domestic violence, financial abuse, or imminent risk of homelessness. In this event, families will be referred directly to the paediatric rehabilitation department social worker. If any child protection concerns are raised, usual mandatory reporting guidelines will apply.

Participants are free to withdraw their consent at any time. Reasons for non-participation will be noted, and the decision not to participate or to withdraw from the study will not affect the participant’s relationship with study hospitals. In such case, the researchers will not collect additional information from the participant, and any identifiable information about them will be removed from the research project.

Dissemination

Our dissemination strategy targets several audiences: (1) people living with cerebral palsy; (2) parents, carers, and family members of people with cerebral palsy; (3) clinicians responsible for delivering health services to people with cerebral palsy; (4) policymakers and health and social service managers; and (5) academics.

Findings will be disseminated at national and international conferences, peer-reviewed journal publications, online webinars, fact sheets, and social media. Findings will be directly disseminated to the NSW/ACT Cerebral Palsy Registers and state-wide not-for-profit organisations providing services for SDH concerns. Outputs will be developed in partnership with the entire project team, including the research advisory groups, to ensure the content is culturally appropriate, sensitive, and digestible to the relevant audience. Easy Read English formats will be made available for children with cerebral palsy and parents/caregivers to cater for the range of abilities and preferences.

This codesign study will inform a future pilot RCT study of feasibility and acceptability, then, if indicated, a pilot clinical trial of efficacy. We will collaborate with all project stakeholders (figure 3), particularly the knowledge translation committee, to further develop the dissemination plans to ensure maximum impact. This committee includes representatives from non-governmental organisations, each NSW children’s hospital, and health sector policy makers to support the development of future research projects and implementation of the study into real-world practice.

DISCUSSION

The SDHs underpin health inequities experienced by children with cerebral palsy. We anticipate that this project will not only inform a future pilot clinical trial of feasibility and acceptability but also generate new knowledge to inform enhanced identification and management of SDH concerns in clinical care, and in turn improve child well-being, parental mental health, and family functioning.

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