Gypsy/Traveller Community Health Worker Service

McFadden, Alison; Biazus-Dalcin, Camila

Publication date:
2023

Gypsy/Traveller Community Health Worker service

Interim evaluation

August 2022

Authors

Alison McFadden, Professor of Mother and Infant Public Health. a.m.mcfadden@dundee.ac.uk

Camila Biazus Dalcin, Lecturer. cdalcin001@dundee.ac.uk

Mother and Infant Research Unit

School of Health Sciences

University of Dundee

11 Airlie Place

Dundee DD1 4HJ

Table of Contents

Introduction

This report presents an interim evaluation of the Community Health Worker service covering the first ten months of implementation.

Context and background

There is longstanding evidence that Gypsy/Travellers living in the UK experience major health inequalities with worse outcomes than the general population and other disadvantaged groups[1,2]. Average Gypsy/Traveller life expectancy is estimated at 11.5 years (women) and 15 years (men) less than the general population[3], with higher rates of morbidity from non-communicable diseases, increased rates of suicide and poorer infant and child health reported[4]. Despite a lack of routine data, research findings consistently show significant gaps between health outcomes for Gypsy/Travellers compared to the wider population.

The reasons for such poor health in Gypsy/Traveller communities are complex; it is unclear how social determinants such as social exclusion, poverty, poor living conditions, low educational achievement and pervasive stigma and discrimination interact with lifestyle factors, health–seeking behaviour and healthcare access[5]. A key barrier to sustained improvement in health is lack of trust between Gypsy/Travellers and healthcare professionals[6]. It is known that Gypsy/Travellers face multiple barriers to accessing responsive health services including upstream public health interventions focused on preventative care such as screening and immunisation. A systematic review[7] identified barriers including difficulties in registering with GPs and dentists, discrimination, lack of understanding from health service personnel, poor communication between healthcare providers and Gypsy/Traveller, low health literacy, lack of trust, and poor-quality care. The review also found a paucity of high-quality evaluations of interventions to reduce health inequalities, and no economic evaluations[7].

---

[1] Cemlyn S, Greenfields M, Burnett S, Matthews Z, Whitwell C. *Inequalities experienced by Gypsy and Traveller communities: a review (Equality and Human Rights Commission research report 12).* Manchester: Equality and Human Rights Commission; 2009

[2] Aspinall PJ. Hidden needs identifying key vulnerable groups in data collections: vulnerable migrants, Gypsies and Travellers, homeless people, and sex workers. Canterbury: University of Kent. Centre for Health Services Studies; 2014

[3] McGorrian C, Frazer K, Daly L, et al. The health care experiences of Travellers compared to the general population: the All-Ireland Traveller Health Study. J Health Serv Res Policy. 2012;17(3):173-180.

[4] Parry G. The health status of Gypsies and Travellers in England: summary of a report to the Department of Health 2004. 2004

[5] Millan M, Smith D. A Comparative Sociology of Gypsy Traveller Health in the UK. Int J Environ Res Public Health. 2019;16(3):379.

[6] McFadden A, Siebelt L, Jackson C, et al. Enhancing Gypsy, Roma and Traveller peoples' trust: using maternity and early years' health services and dental health services as exemplars of mainstream service provision. 2018. https://discovery.dundee.ac.uk/en/publications/enhancing-gypsy-roma-and-traveller-peoples-trust-using-maternity-

[7] McFadden A, Siebelt L, Gavine A, et al. Gypsy, Roma and Traveller access to and engagement with health services: a systematic review. The European Journal of Public Health. 2018;28(1):74-81.

Community-based lay roles have shown potential to enhance equity of healthcare access and reduce health service costs[8]. Such roles work on the premise that role-holders are trusted members of their communities who can facilitate reciprocal relationships and flow of knowledge between communities and health and social care services.

To address the scale and persistence of inequalities experienced by Gypsy/Travellers across Scotland, the Scottish Government and the Convention of Scottish Local Authorities (COSLA) published a joint action plan "Improving the lives of Gypsy/Travellers: 2019-2021". The action plan represents a commitment to human rights and delivering a fairer Scotland. The action plan sets outs commitments aimed at improving the lives of Gypsy/Traveller communities by offering the right to safe and secure accommodation, improving access to public services, addressing financial needs and improving working opportunities, tackling racism and discrimination and improving Gypsy/Traveller representation[9]. The Public Health Practitioner, from the Scottish Public Health Network, worked alongside a Senior Medical Officer in the Directorate for Chief Medical Officer, Scottish Government, to secure two-year funding for the Community Health Worker service.

The Community Health Worker service

The Community Health Worker service is a two-year programme in which Gypsy/Traveller Community Health Workers (CHWs) are trained to provide health advocacy for their community on a wide range of health and social care issues[9]. The aim of the service is to address longstanding health inequalities experienced by Gypsy/Travellers, and to improve their health and wellbeing.

The original intention was that the Community Health Worker service would be delivered by an NHS organisation. However, implementation was significantly delayed by bureaucratic barriers and the Covid-19 pandemic. In 2021, a third sector organisation, Minority Ethnic Carers of People Project (MECOPP) agreed to deliver the Community Health Worker service. The rationale for inviting MECOPP to deliver this service is the long history the organisation has of working with the Scottish Gypsy/Travellers[10]. The community trust and respect this organisation.

NHS Board Chief Executives recommended an NHS Scotland Gypsy/Traveller Steering Group be established whose role, with the Community Health Worker service, would include providing a point of escalation for significant issues, including cross-organisational challenges, and addressing blockages and barriers as they arise. In addition, the Steering Group would support the development and implementation of the service, ensuring its learning, opportunities and challenges are shared across NHS Scotland.

---

[8] Javanparast S, Windle A, Freeman T, Baum F. Community health worker programs to improve healthcare access and equity: Are they only relevant to low-and middle-income countries? *International Journal of Health Policy and Management.* 2018;7(10):943.

[9] Scottish Government. *Improving the lives of Gypsy/Travellers: 2019-2021*. 2019. https://www.gov.scot/publications/improving-lives-scotlands-gypsy-travellers-2019-2021/documents/

[10] Minority Ethnic Carers of People Project. *Gypsy/Traveller Resources.* 2022. https://www.mecopp.org.uk/gypsytraveller-resources

Implementation started in August 2021 with the appointment of the Community Health Team Manager to manage and support the CHWs. The first cohort of five CHWs were recruited in late summer 2021 and, following induction, commenced their roles in late 2021.

The evaluation methods

Aim

To evaluate the implementation of the Gypsy/Traveller Community Health Worker service including the barriers and facilitators encountered and to make recommendations for its future scale-up.

Objectives

1. To identify barriers to and facilitators of the implementation of Gypsy/Traveller Community Health Workers service;
2. To describe the roles, responsibilities and activities of the Community Health Workers;
3. To explore the acceptability, appropriateness, adoption, fidelity and reach of the intervention;
4. To describe any context driven modifications to the intervention as it is implemented;
5. To explore the perceived benefits, disadvantages and any unintended consequences of the Community Health Workers service.

Design

The evaluation design is a multi-method qualitative study guided by the Community Health Worker logic model (Appendix 1) and Proctor's framework of implementation outcomes[11]: acceptability (satisfaction), appropriateness (perceived fit), adoption (uptake), fidelity (delivered as intended) and reach (number of people affected). The study has 3 phases comprising:

1. Interviews with 4-6 key stakeholders;
2. a) three focus group discussions with each cohort of CHWs at different stages of service implementation (early, mid and late), and b) documentary analysis of records of CHWs activities and notes of meetings with the Community Health Team Manager;
3. Individual/small group interviews with 6-10 Gypsy/Traveller people who have engaged with the Community Health Worker service.

To co-ordinate the evaluation, the Evaluation Oversight Group (EOG) was established comprising: a public health practitioner from the Scottish Public Health Network (ScotPHN); the Community Health Team Manager, Gypsy/Traveller Support Service Manager and the

[11] Proctor, E., Silmere, H., Raghavan, R., Hovmand, P., Aarons, G., Bunger, A., Griffey, R., & Hensley, M. (2011). Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. *Administration and policy in mental health*, 38(2), 65–76. https://doi.org/10.1007/s10488-010-0319-7

evaluation team from the University of Dundee. The EOG meet every 6-8 weeks to discuss the service implementation and the evaluation design and progress. The group has met seven times since its inception in August 2021.

Ethics approval was awarded from the University of Dundee School of Health Sciences Research Ethics Committee (UOD-SHS-2021-022) in July 2021.

This interim evaluation reports preliminary findings of:

- Phase 1: Interviews with 4 key stakeholders completed September - December 2021;
- Phase 2a: First focus group discussion and 1 individual interview with CHWs completed January 2022;
- Phase 2b: Analysis of records of CHWs activities.

Preliminary findings

The findings first present the team structure and geographical coverage of the service, followed by the topics and themes raised during interviews and focus group discussions with stakeholders (Phase 1) and CHWs (Phase 2). This is followed by a summary of the activities undertaken by the CHWs based on the documents provided by the Community Health Team Manager. Case studies are presented to illustrate the impact of the service[12]. In-depth analysis is ongoing.

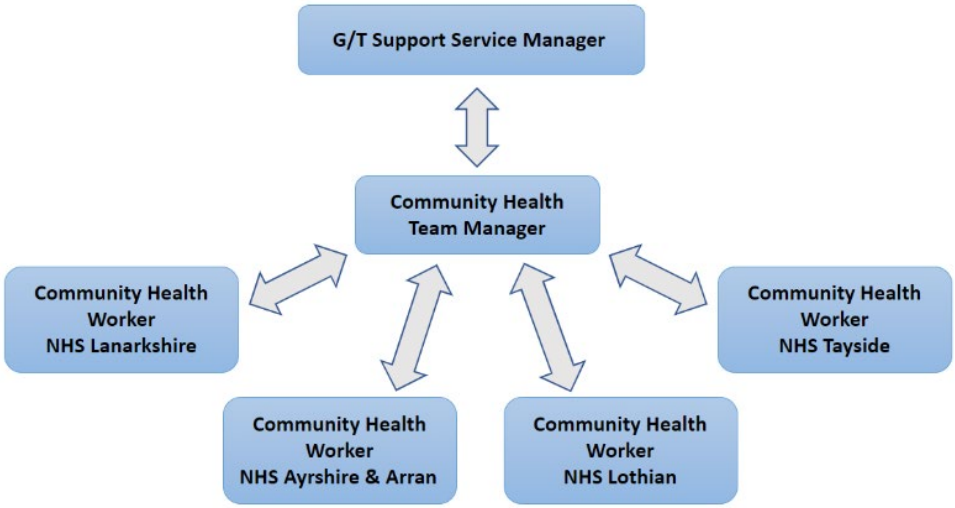
Team structure and geographical coverage

The current structure of the Community Health Worker service comprises a service manager, a team manager and four CHWs. Initially, five CHWs were recruited but one left the post because of personal circumstances. Geographical coverage was led by the recruitment process meaning that the CHWs cover the NHS Health Board area where they live.

Figure 1 shows the current team structure and the geographical coverage by NHS Health Boards.

[12] To maintain anonymity and protect confidentiality, the illustrative case studies presented here combine features from several individual cases.

Figure 1 - Team structure and NHS Health Boards covered



As CHWs are part of the Gypsy/Traveller community, the initial findings show that understanding and being part of the community are essential characteristics for developing the CHW role. During the CHWs recruitment process, the stakeholders prioritised people that were motivated to develop the role rather than focusing on skills, expertise and knowledge related to health issues. The rationale for this approach was to improve the sense of confidence among community members through recognising their unique skills and lived experience as members of the Gypsy/Traveller community. This approach was recognised as supporting community capacity, autonomy and agency, which can lead to positive changes.

The Community Health Worker service has been contributing to Scottish Government health and social care policies, strategies, and priority areas. There is evidence that this service is aligned with Self Management Strategy for Scotland[13], Mental Health Strategy[14], Suicide Prevention Action Plan[15], Equally Safe Strategy[16], Women's Health Plan[17], Primary Care Health Inequalities[18] and Maternity and Neonatal Care Plan[19].

[13] Scottish Government and Alliance Scotland. *Gaun Yersel*: The Self Management Strategy for Scotland. 2008. https://www.gov.scot/publications/person-centred-care-non-executive-members/pages/5/
[14] Scottish Government. *Mental Health Strategy 2017-2027*. 2017. https://www.gov.scot/publications/mental-health-strategy-2017-2027/
[15] Scottish Government. *Suicide prevention action plan: every life matters*. 2018. https://www.gov.scot/publications/scotlands-suicide-prevention-action-plan-life-matters/documents/
[16] Scottish Government. *Equally Safe: Scotland's strategy to eradicate violence against women.* 2018. https://www.gov.scot/publications/equally-safe-scotlands-strategy-prevent-eradicate-violence-against-women-girls/
[17] Scottish Government. *Women's Health Plan: A plan for 2021-2024*. 2021. https://www.gov.scot/publications/womens-health-plan/documents/
[18] Scottish Government. *Primary Care Health Inequalities Short-Life Working Group*: report. 2022. https://www.gov.scot/publications/report-primary-care-health-inequalities-short-life-working-group/
[19] Scottish Government. The best start: maternity and neonatal care plan executive summary. 2017. https://www.gov.scot/publications/best-start-five-year-forward-plan-maternity-neonatal-care-scotland-9781786527646/

Phase 1: Stakeholder interviews

The following summarises the content from four stakeholder interviews. The purpose of the interviews was to gain an understanding of the background, concept, aims and objectives and initial implementation stages of the Community Health Worker service.

Roles of the stakeholders

The four stakeholder participants held roles encompassing national policy, public health and the third sector organisation management team. The participants viewed their roles as improving Gypsy/Traveller health and addressing Gypsy/Traveller health inequalities, designing, implementing and managing the Community Health Worker service, including recruitment and induction of the CHWs.

From concept to implementation

The stakeholders described how the Community Health Worker service was developed to address the significant health inequalities experienced by the Gypsy/Traveller community and in recognition that members from the Gypsy/Traveller Community would be trusted by community members. Two participants described how an initial plan to deliver CHW service via an NHS organisation had been unsuccessful due to bureaucratic barriers, and then the Covid-19 pandemic. The funding was therefore transferred to a third sector organisation which had experience of working effectively with the Gypsy/Traveller community, including during the pandemic. The Community Health Worker service proposal had to be reconfigured to make it more appropriate to deliver at grass-roots level and to align with the third sector organisation funding context. An example given was that the budget had to be re-profiled to include the cost of providing laptop computers and mobile phones for the CHWs, whereas a large public sector organisation could have used existing equipment.

Priority health issues for Gypsy/Travellers

Participants' views of the priority health issues included the social determinants of health such as the impact on health of accommodation, education and discrimination, and the lack of trust between Gypsy/Travellers and health services. Barriers to accessing health services, particularly primary care and preventive services were frequently mentioned as a priority issue.

> *I think one of the first things is accessing NHS services and I'd really like their Community Health Workers to build up the confidence of Travellers in accessing Primary Health Care when they need it. That's what I think would be great. I think people are frightened about using the services. It's like you're scared about using Primary Health Care because of previous experiences. (Interview, Stakeholder 2)*

Two participants talked about issues that had been mentioned by CHWs applicants during interviews. These included emphasis on mental health as a major priority including suicide, anxiety, depression, and isolation and loneliness. This was said to affect people across the lifespan, and men and women. One participant suggested that women often presented with a mental health condition such as anxiety, when the underlying issue was domestic abuse. Other issues raised included childbirth, antenatal and postnatal depression, diabetes,

menopause and men's health. The CHWs applicants were also reported to have mentioned the cumulative effect of multiple health conditions on life expectancy.

> *OK, so mental health and wellbeing came over loud and clear as the top priority and that was for, you know, both men and women, adults, older people, etc. Some people talked about specific conditions. Uh, I that there's a lack of data and research on this, so you know in terms of like a sort of an academic evidence based, I can't point to anything but they talked about some things like diabetes and as an issue. And they talked about almost like the cumulative effect of like multiple health conditions that meant people had much shorter life expectancies, so again, that was a priority about how do we address the impact of multiple health conditions. Look at self-management in order to enable people to have longer and healthier lifespans. And so yeah, so those were the two main things. Yeah, mental health wellbeing and shorter lifespans overall. (Interview, Stakeholder 4)*

Anticipated impact of the Community Health Worker service

At a policy level, it was hoped that CHW service would result in Gypsy/Travellers being more involved in health care decisions, and being able to make informed choices about their health, and that services would be redesigned to be more appropriate to Gypsy/Traveller needs. Scalability and sustainability were also critical outcomes for stakeholders.

Impact on the CHWs were also important to stakeholders including building capacity in the community through the confidence and expertise of the CHWs. Stakeholders hoped that CHWs would flourish within the role, gain qualifications and maintain employment.

In the early stages of the service, community acceptance of and trust in the CHWs were hoped for outcomes. Stakeholders recognised the lack of NHS data on Gypsy/Travellers' service engagement and health outcomes, and the inappropriateness of setting targets for numbers of people engaging with health services. However, there were hopes that there would be self-report of the number of people reached by the CHWs and an increase in GP registrations. Building confidence through the CHWs was seen as an important way to address poor mental health.

Policy alignment

Participants highlighted other policies and strategies that CHWs could contribute to such as Realistic Medicine led by the Chief Medical Officer. A critical aspect was that the Community Health Worker service could enable Gypsy/Traveller voices to be heard in national policy discussions to enable consideration of cultural norms and sensitivities. One of the stakeholders described some of the topics that should be included in policy documents:

> *So all these things about accommodation, education, discrimination, prejudice, they all are interconnected with health and health interconnects with them. This health meaning, physical and mental and emotional wellbeing and underpinning all that was the low expectations and mistrust. So we have to tackle all this. None of that is recognised in the policy documents. (Interview, Stakeholder 3)*

Key challenges

Stakeholder participants highlighted what they perceived to be the main challenges for the Community Health Worker service implementation. A key concern was role boundaries and unrealistic expectations of the CHWs within the role. An example was cited of the CHWs being asked to be involved in accommodation issues which is beyond the remit of the role. However, one participant commented that issues such as poverty and poor accommodation impact directly on health making it difficult to draw boundaries. There was concern about the potential for a Gypsy/Traveller to be supported by a CHW to access a health service and then experience discrimination from health service staff. It was felt this could impact significantly on community confidence in the CHWs. There were concerns about retention of the CHWs and risks of them leaving due to sickness or because the role was not what they had expected. Finally, one participant expressed concern about how the change of status of the CHWs i.e., to a paid role, might affect their relationships with the community such as introducing a power differential.

Some challenges related to the change to implementation by a small third sector organisation compared to the original plan of delivery by a large public sector organisation. A further challenge to the budget was that it had been envisaged that the CHW contracts would vary in the number of hours specified according to the CHWs individual preference. However, the CHWs had all wanted the maximum hours on offer putting pressure on the budget and reducing the number of CHWs that can be employed.

Concern about a further lockdown due to Covid-19 was also mentioned.

Phase 2a: Community Health Worker focus group discussion and individual interview

The following is a summary of the focus group discussion and individual interview with five CHWs (four participated in the focus group discussion and one in an individual interview). It should be noted that the focus group and interview took place about one month after the CHWs had commenced their roles, so it was very early in the service implementation. We present case studies as examples of the some of the comments made during the focus group discussion and interview.

Motivations for applying for the role

There was consensus among that CHWs that there were two key motivations to applying for the role. The first was that it was a role that had been talked about within the community for many years. They all felt they had been fulfilling the role informally to some extent for their communities prior to applying. The second was awareness of the needs of the community in terms of health challenges and accessing health services. One CHW also talked about having confidence to do the role as there were no pre-requisite qualifications or special skills needed, only the desire to do it.

Benefits of the role

Many benefits of the role for themselves and their community were highlighted. They were unanimous that they were enjoying the role and were very appreciative of the support provided by the employing organisation. A key benefit for the CHWs was the increase in confidence specifically because of the status the role brought in their dealings with public

sector workers. The most frequent phrase used was 'it opens doors'. The quote shows the importance of the CHW status:

> *But see when you walk in, they only see you as this Traveller coming from the site. They immediately don't want to deal with you, and they immediately get an attitude with you because they can. But when you say you're a Community Health Worker, they take you seriously instead of just thinking it's Traveller who's just coming up to shout and scream at them. They actually then have to do their job and treat you like a person. (Focus Group, CHW1)*

Examples were given of being able to access information, and being respected and taken seriously by local authority and health service staff. Stark comparisons were made between attitudes of others towards them as Gypsy/Travellers and attitudes when they introduced themselves as CHWs working for an organisation.

Case study 1: Access to prescription

Gypsy/Traveller who was having difficulty obtaining a prescription because the GP practice had removed them from their register. The GP practice requested proof of identity and address to re-register. When a CHW phoned the practice and said that she was a CHW, the staff were very helpful, and the issue was resolved quickly.

All the CHWs were positive about the benefits of the role for the health and wellbeing of their communities. A perceived key benefit for the Gypsy/Traveller community was that the CHWs were non-judgemental and understood the culture and needs. The CHWs thought a positive change was that Gypsy/Travellers would not feel awkward to approach them because of the formal role. The CHWs felt that a benefit they brought was facilitating access to and allaying fears about health and social care professionals. This was particularly related to interactions with social workers. It was also said that the funding of the roles demonstrated to the community that their needs were recognised by policy makers. One of the CHWs describes the feedback they had from a health visitor:

> *Well, I was just speaking to a health visitor because one of my members of my community asked me to. And when arrived she was so positive. She was saying we need more people like you and she's been out to sites and it would be great to have you on board. She said that I can signpost people or and I know [the issues] better than her so she took all my contact details. (Focus Group, CHW2)*

Importance of trust

Building trust was seen as critical to the success of the CHW role because no-one would seek their support without trust. Several dimensions of trust were highlighted. One was the central role of confidentiality. One CHW commented that women understood that everything between the CHW and Gypsy/Travellers seeking their support would be kept confidential but that men would be more cautious. The CHWs discussed the importance of trust for the job role:

> *I think it's like you could never do this job if people did not trust you or if people didn't feel like they could speak to you. I think it's completely essential that we have trust… We just wouldn't be able to do the work that we're doing because nobody would come with the information because they'd be worried people would talk about their business [to others]. (Focus group, CHW1)*

A second dimension of trust was Gypsy/Travellers recognising that the CHWs were there to help them and had their 'best interests at heart'. This was linked to understanding the culture.

Case Study 2: Understanding the community

CHWs who understand the culture and the traditions of the community can recognise that a Gypsy/Traveller who experienced disabilities would not be better off in a house. Because CHWs are part of the community, they understand the impact of changing places on the individuals' mental health and that this would outweigh the benefits of having mobility aids in a house.

Challenges and concerns

The main challenge the CHWs mentioned was learning new technological skills. How to use a laptop and how to attach a file to an email were specific examples given. While the technology was said to be a challenge, it was also clear that learning new skills increased the CHW's confidence. The CHWs were very appreciative of the support provided by MECOPP in this and other aspects of their roles.

The CHWs' key concern was about what would happen to the role at the end of the two years' funding. This was at a personal level with one CHW asking if they could still call themselves CHWs even when they were no longer employed in that role. However, the greater concern was that the CHWs would develop relationships and build trust and then the Gypsy/Traveller community would feel let down if the service disappeared. This was compared to other services for Gypsy/Travellers that had come and gone due to short-term funding. One of the participants explained the importance of the continuity of the service:

> *It [Community Health Worker service] has to go further as to continue learning, has to, whether it's us or whether it's someone else, it has to continue. Because I see this is a massive breakthrough… And bring the issues out, bringing them to light, understanding the issues rather than just bringing the issues to light. Understanding the issues. Really understanding them. I think it's essential that it continues as I say whether it's awesome, whether it's someone else, but it has to continue. (Focus Group, CHW3)*

The CHWs recognised that their role was part of the Scottish Government's action plan to improve the lives of Gypsy/Travellers in Scotland and questioned what the government wanted to gain from the CHW service and whether the project was 'ticking a box'. They talked about the importance of the CHWs feeding back on the impact of the wider Gypsy/Traveller action plan. The CHWs talked about the accommodation component of the

plan and emphasised that local authorities were improving the quality of some accommodation but that this was resulting in even fewer pitches being available, so wasn't addressing the problem.

Phase 2b: Summary of activities and reach of CHW service

The summary below is of activities undertaken by the CHWs up until the end of June 2022. The documents provided by the Community Health Team Manager comprised notes of meetings between the Community Health Team Manager and the CHWs (both group and one-to-one meetings) and communications sent by the CHWs to the Community Health Team Manager including summaries of activities and accounts of individual cases. These documents have been analysed descriptively noting reach of the service, training undertaken by CHWs, health issues encountered, problems that are broader than health but directly influence health, activities and actions taken by the CHWs and, where available, outcomes of those actions. Many of the health issues are complex and the situations are ongoing.

Reach

The CWHs have had initial individual contact with around 370 Gypsy/Travellers from January 2022 until June 2022, covering four the NHS Health Boards (Ayrshire and Arran, Lanarkshire, Lothian and Tayside). In addition, the CHWs have had several follow-up meetings with many of these individuals, with inessive input ongoing for some complex situations. The actual reach will be much higher because support and information from the CHWs has influenced family members. This makes it challenging to 'count' contacts. The CHWs have also been involved in group activities through which they have reached more community members.

Training

During the induction to the new role, the CHWs undertook training delivered by MECOOP. This training and induction pack included: Confidentiality, Health & Safety (Covid-19), Computer & Internet Safety, Boundaries, Active Listening, The Social Model of Health, Community Mapping, Community Development approach, Determinants of Health & Health Inequalities, and Reflective Practice.

The CHWs have also had the opportunity to take part in other training, such as:

- Cardiopulmonary resuscitation (CPR) training the trainer (Save a Life Scotland);
- National Screening & early detection programme (Kathryn Sinclair NHS Lothian);
- Head & Neck Cancer info (NHS Screening and Early Detection Team);
- Sexual Health/Health promotion (Sexual Health and BBV Team NHS Scotland);
- Mental Health First Aid Course (MHFA/ Lancashire NHS);
- Domestic Abuse/Gender-based Violence & Coercive Control (Turas/Scottish Women's Aid).

Case Study 3: Impact of training

Because of an informal family visit, one of the CHWs was able to address a case of domestic abuse and offer the right approach based on lessons learnt during a training session. As a result, the CHW knew how to manage the situation with a person-centred approach. This showed the importance of CHWs being part of the community (right person, right place, right time) and the impact of training on their role.

Issues identified and impact of individual casework

The most frequent theme was mental health encompassing low mood, depression, stress and anxiety, suicidal feelings, addiction, schizophrenia and post-traumatic stress disorder. The CHWs have supported both men and women with mental health problems. Physical health problems included diabetes mellitus, women's health issues (e.g., access to contraception, polycystic ovary syndrome), suspected heart problems, sciatica and inflammatory bowel disease. The complete list of issues identified by CHWs is available in Appendix 2.

Many of the individuals/families supported by CHWs have complex needs and multiple problems with physical and mental health as well as accommodation/housing challenges. For example, mental health issues were frequently associated with accommodation/housing problems. Experiencing discrimination and racism when accessing services was an additional factor exacerbating health challenges. A further problem in access to health services was that post on Gypsy/Traveller sites is often delivered to a central point and then distributed to individual recipients by a gatekeeper such as the site warden. As well as being illegal, this can result in delays in receiving appointment letters.

Most of the individual advocacy work undertaken by CHWs involved helping Gypsy/Travellers to access services and/or achieve a satisfactory response from services. Typical scenarios were either that a Gypsy/Traveller lacked confidence to approach services or did not know where to find help. Case studies 4 and 5 illustrate events in which the CHW made a difference in health care access.

Case study 4: Access to services – Covid-19 vaccination and minor health problems

A Gypsy/Traveller did not know how to have a Covid-19 vaccination without an address, and another did not want to go to a busy GP practice during the pandemic with a minor health problem. For the former, the CHW took the Gypsy/Traveller to a drop-in clinic where they received a vaccination. The latter was taken to a pharmacy by the CHW to register for the minor ailments scheme and received appropriate medication. These actions support the increase in the uptake of the Covid-19 vaccine and Pharmacy First Awareness Raising.

Case study 5: Access to dental services

Gypsy/Travellers shared with CHWs their difficulties accessing NHS dental services and the need to pay for dental treatment, resulting in years without seeing a dentist. The impact of not accessing the dentist was associated with pain and worsening symptoms. In different situations, the CHWs called the dentists, made sure Gypsy/Travellers registered with the dentist, booked appointments and accompanied individuals to their dental appointments. The main challenges the Gypsy/Traveller community raised were delays in receiving check-up reminders and the requirement to provide proof of address to register with a dentist.

There were numerous stories of Gypsy/Travellers who had tried unsuccessfully to receive timely care which the CHW was able to resolve quickly e.g., a Gypsy/Traveller who had contacted the GP practice several times for results of a test taken four weeks previously. The CHW contacted the practice, and the results were available the same day. The CHWs reported that, on occasions, they had to be assertive and highlight unacceptable care to achieve satisfactory responses from healthcare providers. There were numerous examples of CHWs accompanying Gypsy/Travellers to appointments or being present when home visits were made to provide reassurance and facilitate effective communication. In one case, the CHW was present during a visit by social workers to allay fear of consequences for children:

> *But for Travellers this they hear the word social worker and they just shy away but if they had people that actually was from their own communities they would listen. This is what this is about to help you in that situation, that's it. (Focus Group, CHW3)*

Supporting mental health involved supportive visits and suggesting other activities to enhance mood e.g., physical exercise or support group attendance. The CHWs were also supporting Gypsy/Travellers to address accommodation problems e.g., through contacting relevant local authority services or facilitating acquiring a doctor's letter to support a housing application.

Even at this early stage of the service, there are some tangible outcomes such as the Covid-19 vaccine received, previously undiagnosed conditions being treated or investigated, one person in temporary accommodation and on a housing list. There are many less tangible outcomes such as the trusting relationships developed with community members, increased confidence of the CHWs and the people they help and support through ongoing challenging situations. These are difficult to measure, especially at this stage of the project. A strong theme throughout the reflections of the CHWs is that the people they help would not trust anyone outside the Gypsy/Traveller community and therefore problems would not have been disclosed and addressed. A key factor for developing trust is reported to be confidentiality. The CHWs have received feedback which suggests their services are welcomed and very much appreciated by the community.

Community impact

At a collective advocacy level, the CHWs have identified numerous issues that they have addressed or wish to address at community and service provision levels. Some examples are:

- Access to prescriptions when community members are travelling outside their localities
- Barriers to women's sexual and reproductive healthcare and screening
- Inconsistent information during the Covid-19 pandemic
- Young people's mental health
- Barriers to registering with dentists and opticians (requirement for proof of address and ID)
- Lack of support (health, social care and education) for families with children with special needs e.g., autism, bowel disease
- Diabetes mellitus and prevention of complications e.g., importance of foot care
- Impact of bullying and racism towards children at school on family health and wellbeing, and education of children

Case study 6: Uptake of cervical screening

In one of the areas covered by the service, CHWs identified that 15 out of 30 women who took part in a focus group had never accessed cervical screening. The barriers to cervical screening included not receiving invitation letters (lack of fixed address), lack of confidence to access healthcare services, and embarrassment associated with community gatekeepers (e.g., site wardens) receiving personal letters. The CHW's input was to explain the importance of the test, support individuals in booking appointments, and accompany women to their cervical screening appointments.

The CHWs have engaged in a range of activities to address these challenges encompassing initiating/attending meetings with other services/sectors, running community/information groups e.g., women's health groups, adapting and distributing health educational materials for community members, direct contact with services e.g., one CHW is now able to fast track Gypsy/Traveller women to contraception services; and finding dentists and an optician who will register patients without need for proof of address. A further aspect of the CHW role is to promote their role both to Gypsy/Travellers and to service providers. Several issues have been escalated by the CHWs to the Public Health Practitioner from the Scottish Public Health Network who has taken additional action. For example, the access to prescriptions when travelling was escalated to Scotland's Chief Pharmacist who provided information that the unscheduled care Patient Group Direction (PGD) allowing community pharmacies to provide patients with up to one prescribing cycle of their regular repeat medicines could be an alternative to registering with a GP as a temporary patient.

Progress mapped to logic model

The Community Health Worker service logic model (see Appendix 1) which underpins this evaluation identifies outputs to be monitored and outcomes to be evaluated. The interim evaluation findings have been mapped against the outputs and short-term outcomes as shown in Table 1 below. The table also highlights the sources of evidence for the judgements made. Table 1 shows that the outputs are in-progress and on track. Recruitment of the Community Health Manager is completed. Excellent progress is being made towards achievement of the short-term outcomes for the CHWs. More data to evidence achievement of these outcomes will be available as the evaluation progresses with further focus group discussions and analysis of the CHW activities. The outcome *CHWs' increased confidence, skills, and ability to effect change and influence local NHS, health, and social care decision-making* may be more challenging to evidence. It is too early to evaluate outcomes for the NHS, health and social care and third sector, and for the Gypsy/Traveller community. However, there are many examples from the evidence from the CHWs presented in this report that show how these outcomes might be achieved.

Table 1 - Summary of the interim evaluation against the logic model: outputs and short-term outcomes

Outputs to be monitored	**Progress/data**		**Outcomes: Short term – Year 1**	**Source of evidence/progress**
Community Health Manager recruited	Completed		CHWs Feel more motivated, empowered, and confident due to being recruited to and undertaking their role	Focus group - CHWs are highly motivated and feel confident
Number of CHWs recruited	Cohort 1 Sept 21 7 applicants 5 appointed 1 resigned due to ill health		CHWs Increased awareness and understanding of the health and well-being issues affecting their community, social model of health, social justice and health inequality	Focus group - CHWs had pre-existing awareness of health issues and inequalities. CHW activities: demonstrate increasing awareness of health issues, individual's rights to care and support from statutory services and inequalities.
No. and type of training provided to CHWs	IT skills; Suicide prevention; Confidentiality and boundary; Health Issues in the Community (HIIC); suicide and domestic abuse		CHWs increased knowledge and understanding of NHS & other statutory services' systems and services	CHW activities – CHWs are developing knowledge of services and systems
No. of resources sourced or adapted and distributed, and topics covered	CPR, neck and throat cancer, screaming and vaccination, Covid-19, GP access cards, agreement with the Scottish government on how Gypsy/Travellers would like to be treated		CHWs Increased confidence, skills, and ability to effect change and influence local NHS, health, and social care decision-making	Presentation at Health Improvement Scotland seminar
No. of people contacted Geographic reach	370+ contacts: 07/22 Ayrshire and Arran, Lanarkshire, Lothian, Tayside		NHS, HSC and third sector have improved understanding of health priorities of the community and barriers they face in accessing their services	Future stakeholder interviews To discuss adding service provider interviews Discussions with Steering Group
Type of health priorities identified	CHW focus groups and summary of activities e.g. mental health, diabetes, sexual and reproductive health, menopause, continuity re prescriptions, access to opticians and dentists; child health		G/T community: More understanding of issues affecting their health and well-being and actions they could take individually and collectively to improve it e.g., vaccinations, screening, antenatal care, mental health support, lifestyle change, COVID public health messages;	Future interviews
Type of contacts: e.g., advocacy, advice, information	CHW activities: 1-1 support, liaison with statutory services (health, housing,		G/T community: - Confidence in using resources to improve health & well-being.	Future interviews

sharing, 1:1 support, referral, group support, link-up	education, social work) information sought and provided (Covid guidance, accessible dentists and opticians), signposting to other services and support, joint facilitating groups (women's health group and young person's group), networking and strategy groups		For example, COVID specific resources; It's Ok to Ask and so on;	
No of referrals to MECOPPs counselling, financial resilience, carers support	Discuss with the Steering Group if the number of referrals is needed		G/T community Increased knowledge and understanding of NHS & HSC systems and services	Future interviews
No of referrals to other services (third sector and statutory services)	Discuss with the Steering Group if the number of referrals is needed.			
TOR agreed and No. of Steering Group meetings	ToR agreed Meeting 1: 06/22 Meeting 2: 10/22			
No. of awareness raising sessions, to whom and No. attending	Workshops and information sessions Cholesterol and diabetes sessions (support of NHS staff) 12 women attended 3 workshops 9 women are currently attending ongoing information sessions Women participating in the workshops share information with their family members and friends (part of Gypsy/Traveller culture)		Key Completed/achieved In-progress/on track Not started/supporting data not yet collected	
Issues escalated to the Steering Group/national forums, action taken, and outcome achieved.	Pharmacist, access healthcare services (GP registration), maternity, blue access cards, CHW spoke at an online seminar - Healthcare Improvement Scotland, meeting Public Health Ministers			

Lessons learnt

The interim evaluation demonstrates successful early implementation of the Community Health Worker service. The four CHWs have addressed a wide range of health and social problems affecting the Gypsy/Traveller community in four Health Board areas of Scotland. The CHWs have overcome barriers to accessing health and other statutory services for individual Gypsy/Travellers and their families. The CHWs have also provided information to help the wider Gypsy/Traveller community to improve their health and access services. Possibly even more importantly, the CHWs have already increased their confidence and skills, have developed trust with Gypsy/Travellers in the geographic areas where they work, and have forged productive relationships with some key service personnel. Through MECOPP and the Public Health Practitioner, issues have been escalated to involve further services and national policy. The Steering group will provide a platform for future escalation of health and service problems.

The evaluation has also identified some challenges to the Community Health Worker service reaching its full potential to improve Gypsy/Traveller health and wellbeing, reduce inequalities and ensure that statutory services meet the needs of the community. These challenges include:

- There are only 4 CHWs working part-time, with limited funding available to increase the number and geographical spread of the service.
- The funding has been provided for two years which gives limited scope to demonstrate its impact and threatens sustainability. This is causing anxiety for the CHWs.
- Stakeholders report demand for the service from Health Boards without a CHW which cannot be met within the current funding and capacity.
- The CHWs are piloting approaches in different areas to develop promising interventions to improve healthcare outcomes for the Gypsy/Traveller community. Time is needed to assess the effectiveness of these interventions and for scale-up.
- There may be unrealistic expectations of the service from public bodies that have requested specific actions such as working on registration with dentists, vaccination rollout across lifespans and pharmacy first awareness. As well as being unrealistic within the capacity of the CHWs, these demands conflict with the focus of the service which is the needs and demands of the Gypsy/Traveller community.
- There are data challenges to conducting the evaluation. Due to the organic and fluid characteristic of the service and cultural issues (e.g. is it diffusion among families), it is challenging to assess the number of people that have been reached, helped and influenced. The evaluation team are working with MECOPP to optimise data capture and to provide the quantitative evidence needed to demonstrate the impact of such a complex and diffuse intervention. A strategy is also needed for evidencing impact on health services.

Acknowledgements

Funding

This report presents interim findings of an independent evaluation funded by the Scottish Government through the charity MECOPP. The views and opinions expressed in the report are those of the authors and do not necessarily reflect those of the Scottish Government.

The report presents interim findings as the evaluation is ongoing. A final report will be published in due course.

We would like to thank the following people for their contribution, advice and guidance:

The Project Oversight Group: Suzanne Munday, Charise Barclay-Daly, Kate Burton

Dr Lynne Tammi

The Gypsy/Traveller Community Health Workers in NHS Ayrshire and Arran, NHS Lanarkshire, NHS Lothian and NHS Tayside

The NHS Scotland Gypsy/Traveller Steering Group

Stakeholder interview participants

Appendix 1: Logic model of the Community Health Worker Service

(Updated August 2022)

Problem/ context	Intervention strategy	Outputs to monitored	Outcomes to be evaluated		Impact
			Short Term Year 1	Med term Year 2	
Gypsy/Travellers (G/Ts) have poor health outcomes • Reduced life expectancy; • High rates of mental health problems; including suicide rates • High rates of long-term conditions; • High rates of child morbidity and mortality; • Lower uptake of vaccinations and screening; • Increased risk of COVID. **Gypsy/Travellers face barriers to using health services** • Barriers to registering with GPs, dentists, opticians and access to health services;	**Approach** Asset building theory. **Key Strategies** • CHW role and responsibilities include information sharing, advocacy, advice, 1:1 and group support, onward referral/signposting. • CHW recruitment process accounts for differing literacy, numeracy and digital skills/access. • G/Ts with a strong and positive sense of cultural identity, awareness of cultural variations among their communities are recruited and supported as CHWs. • CHWs are embedded within their local community within a Health Board locality • Community Health Manager develops and delivers induction programme • Community Health Manager provides 1:1 and group	Third sector: Community Health Manager recruited; Third sector: No. of CHWs recruited; Third sector No. and type of training provided to CHWs CHWs: No of resources adapted/ distributed, topics covered CHWs: No. of people contacted and geographic reach CHWs: Type of health priorities identified; CHWs: Type of contact e.g., advocacy, advice, information sharing, 1:1 support, referral, group support, link-up; CHWs: No of referrals to MECOPPs counselling, financial resilience, carers support; CHWs: No of referrals to other services (third	CHWs: motivated, empowered, and confident to undertake their role; CHWs: increased awareness and understanding of the health and well-being issues affecting their community, social model of health, social justice and health inequality; CHWs: increased knowledge and understanding of NHS & other statutory services' systems and services; CHWs: increased confidence and skills to effect change and influence local NHS, and health decision- making; NHS and third sector: improved understanding of health priorities of the G/T community and barriers they face in accessing services; G/T community: More understanding of issues affecting their health and well-being and actions they could take individually and	CHWs: gained skills, knowledge and experience which are transferable to other situations; G/T community: CHW role and their impact are viewed positively and trusted by G/T communities; G/T community: More confident in accessing and navigating NHS and statutory services; G/T community: individuals, families, and carers understand how to plan for continuity of care, medication, and treatment if they move on, or are moved on, while they are unwell, receiving care or treatment; Local NHS and third sector: report increased awareness of the health issues affecting the G/T community and what they have put in place to make their services more accessible;	Reduced inequalities in health outcomes; Improved access and timely and appropriate use of NHS/statutory and third sector services; Outcomes of the service are sustained in local areas; Outcomes of the service are disseminated to relevant bodies and agencies e.g., NHS/ H&SC, governments, relevant third sector organisations across Scotland; Learning is used by NHS and statutory services in all areas of Scotland to inform service re-design and programme development to improve the health outcomes for Gypsy/Travellers.

• Discrimination and stigma; • Low health literacy and literacy; • Lack of trust in public services • Lack of information on the most appropriate service to access for their needs. **Community-based lay roles show promise to increase trust, equitable health service access, and improve health & well-being outcomes; evidence of their effectiveness in marginalised communities is lacking.**	support and training in response to CHW needs • CHWs are trusted by the community who will tell them their health priorities. • CHWs are supported by Community Health Manager to provide appropriate responses to community priorities. • Existing resources are adapted to be culturally appropriate for G/T • The Steering Group (SG) provides a point of escalation for issues identified by the Community Health Manager, including cross-organisational challenges, and addresses blockages and barriers. • Scottish NHS/H&SC Gypsy/Traveller Forum members link with local CHWs and support them regarding heath and care information, and information to navigate the local health and care services; • Community Health Manager and CHWs provide awareness sessions for third sector and NHS on health issues affecting G/T community and barriers to accessing services.	sector and statutory services); SG/NHS: TOR agreed, and no. of Steering Group meetings held; SG/NHS: No. of awareness sessions, No. and who attending; SG/NHS: Issues escalated to the Steering Group/national forums, action taken, and outcome achieved.	collectively to improve it e.g., vaccinations, screening, antenatal care, mental health support, lifestyle change, COVID public health messages; G/T community: confidence in using resources to improve health & well-being e.g., COVID specific resources; It's Ok to Ask; G/T community: increased knowledge and understanding of NHS systems and services;		

Appendix 2: Issues identified by CHWs (Jan-Jun 2022)

Health promotion/education and access to services

- Health information that needs adapting to be culturally and literacy sensitive
- Contraception information and access to services
- COVID and vaccination information
- Minor Ailments Scheme - information on how to apply
- Registering with frontline services
- Issues trying to register with front line services; opticians/dentists/doctors
- Accessing local authority leisure centres
- Escalate/chase up hospital referrals through doctor surgery
- Access to dental care for treatment/emergency treatment
- Retrieving prescriptions whilst shifting/on the road
- Providing information on health services and benefit entitlement; blue badge
- Occupational Therapy (OT) services and setting up appointments
- Providing information and myth-busting on smear tests
- Prostate information

Health issues

- Mental Health: Depression/Anxiety/Stress; Bipolar Disorder; Schizophrenia; Addiction/alcohol and/or drugs; Panic attacks
- Sexual and reproductive health: Premature Birth, Gestational Diabetes; COVID-19 during pregnancy; Polycystic ovary syndrome; Miscarriage; Rape
- Long term conditions: Obesity; Cholesterol; Diabetes type 1/ type 2; Diabetes complications – sore feet; Incontinence; Stomach/bowel problems; Chronic obstructive pulmonary disease; Thyroid/Graves' disease; Arthritis
- Diet
- Cancerous skin/moles
- Acute Trauma
- Eating Disorders
- Physical disabilities

Wider issues

- Domestic abuse
- Inadequate housing
- Homelessness
- Educational rights for children
- Disability rights
- Racism/ Prejudice/ Discrimination
- Attending/supporting 'Work Focused Interviews' with community members
- Access to additional support for learning (ASL) within education (for children with additional support needs or a medical diagnosis)