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Programa Maior Cuidado:

an integrated community-based intervention on care for older people[1]

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Abstract

This report presents an overview of a novel community-based intervention for older people living in deprived neighbourhoods in the Brazilian city of Belo Horizonte: Programa Maior Cuidado (PMC). Since 2011 PMC has been jointly run by the municipal Departments of Health and Social Assistance to support dependent older people living in vulnerable families. These families receive up to 20 hours of support a week from professional family care support workers. Health centres and social assistance posts hold joint monthly case reviews and work closely with family care support workers to anticipate and respond to new problems. Between 2011 and December 2022, 3,062 families had received support or were continuing to do so.

Drawing on a set of qualitative and quantitative evaluations, we show that PMC operates effectively and appears to generate a range of positive effects. These effects include enhanced health and wellbeing of older people, reducing the stress and burden of family carers and improving the efficiency of outpatient and inpatient health service use. PMC also provides a valuable livelihood opportunity for the caregivers it employs. A cost analysis estimates that the monthly per capita cost of PMC in April 2023 was 916.2 reais (US$173), which is substantially less than alternative interventions.

These positive evaluations have led Belo Horizonte municipality to extend the scheme and the

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Federal Ministry of Health to support similar pilots in new cities. Future evaluations of these pilot schemes will add to the available evidence about PMC and its potential suitability for other parts of Brazil and similar countries.

Key words: Long-term care; older people; primary health care, social care, community.
JEL classification: I10, J14, H5, J18

Abbreviations and acronyms

BPC	Brazil's social assistance pension (Benefício de Prestação Continuada)
CRAS	Social Assistance Reference Centre (Centro de Referência de Assistência Social)
DoH	Department of Health, Belo Horizonte Municipality
DoSA	Department of Social Assistance, Belo Horizonte Municipality
FCSWs	PMC family care support workers
LTC	Long-term care
PAI	Programa Acompanhante de Idosos, São Paulo Municipality
PMC	Programa Maior Cuidado, Belo Horizonte Municipality
SUAS	Brazil's Unified National Social Assistance System (Sistema Único de Assistência Social)
SUS	Brazil's Unified National Health System (Sistema Único de Saúde)
UBS	Community Health Centre (Unidade Básica de Saúde)

Introduction. Responding to the challenges of population ageing in low and middle-income countries.

In 2021 there were over 300 million people aged 70 or more in low and middle-income countries (United Nations, 2022). By 2050 the number of people aged 70 or more in low and middle-income countries is projected to be three times greater than in high-income countries, and to exceed one billion by 2056 (United Nations, 2022). Population ageing in low and middle-income countries is occurring in contexts of limited resources for health services and, at best, incipient social care systems. Without substantive policy responses, these trends will quickly overwhelm service capacity. In high-income countries, integration between health and social care, with a focus on community provision is seen as essential for the sustainability of health systems (Reed et al, 2021). Potential benefits of integrated community-focused strategies include prevention or timely treatment of conditions that would otherwise require hospital care, avoiding hospital admissions for conditions amenable to ambulatory care and reducing delays to hospital discharge (Lloyd-Sherlock et al, 2020). This paper examines the effects of a related intervention in Brazil.

In Brazil the number of people aged 70 or over will almost treble between 2020 and 2050, from 13 to 37 million (United Nations, 2022). Due to prevalent disability and chronic comorbidities, around 20% of this population is currently care-dependent, with higher rates among the poor (Aranco et al., 2022; Peroni et al., 2023). From 2009 to 2015 people aged 60 or over accounted for 29% of Brazil's hospital admissions and 52% of intensive care unit admissions (Dias and de Barros, 2019). From 2000 to 2013 31% of inpatient hospital spending on people aged 60 or over was for conditions amenable to treatment in other settings (de Souza and Peixoto, 2017). A survey of hospitalizations of people aged 60 or over in Rio de Janeiro reported 2,260 cases remained for over a year, mainly due to inadequate care in the community (Romero et al. 2010).

The large majority of those older people in low and middle-income countries with care needs continue to live at home and receive support from family members on an unpaid basis (WHO, 2021). Nevertheless, access to family support is far from complete. A national survey in Brazil found 51 per cent of older women and 45 per cent of older men with care needs and who lived with younger adults reported they received no support (Camarano, 2017). There are evident gaps in the willingness and capacity of families to provide care to older members on an unpaid, unsupported basis. These gaps have spurred a growth in other types of long-term care (LTC) provision. These include the rapid extension of residential LTC facilities, such as care homes and nursing homes. For example, in 2010, Argentina's Union of Gerontological Service Providers estimated the country contained 6,000 residential care homes. In Brazil during the COVID-19 pandemic over 8,000 care homes joined a new national provider network (Carvalho et al, 2022). Typically, responsibility for these facilities is shared between government agencies, with ministries of social development/assistance/welfare often taking the lead role.

There is, however, growing evidence that LTC facilities do not represent the best option for meeting the care needs of many older people. First, the great majority of older people prefer to remain in their own homes or live with relatives, whenever possible (WHO, 2015). Second, there is emerging evidence of poor quality and weak regulation of LTC facilities, many of which are operated by the private sector (Lloyd-Sherlock et al, 2021a). Furthermore, the cost of establishing

and running LTC facilities, while ensuring they comply with acceptable norms and standards of care is considerably higher than most older people in low and middle-income countries can afford (Lloyd-Sherlock et al., 2021a). Over the past 25 years, in response to similar concerns, many high-income countries looked to develop alternative approaches to enable older people to remain at home, while ensuring their needs are still met (WHO, 2015). In low and middle-income countries, national and local governments are now starting to consider similar strategies (Lloyd-Sherlock et al., 2020b; Cafagna et al., 2019).

As part of this new thinking about LTC policy, there is increasing awareness about the potential benefits of strongly integrating LTC and health services for older people (The Kings Fund, 2018). Evidently, there are strong connections between poor health, frailty, and care needs in later life. Chronic and comorbid conditions are associated with gradual functional decline, while more acute health episodes (for example falls or strokes) usually trigger a more sudden onset of care needs (WHO, 2015). Good health care in later life can reduce overall demand for LTC. For example, effective treatment of chronic conditions like hypertension significantly reduces the risk of acute episodes such as stroke, which in turn is one of the main causes of disability and hence care dependency among older adults (Campbell et al., 2019). Similarly, effective collaboration between primary health care workers and family caregivers can reduce the risk of falls, as well as conditions like urinary tract infection, a leading cause of hospitalization of older people in low and middle-income countries (de Souza and Peixoto, 2017).

Even before the onset of the COVID-19 pandemic, there was emerging evidence of the benefits that can result from integrating LTC and mainstream health services for older people (Sempé, Billings and Lloyd-Sherlock, 2019). These can include more efficient use of health services and improved health outcomes for both older people and their caregivers. During the early months of the COVID-19 pandemic, a number of policy failures resulted from mis-coordination between LTC and health services. These included failures to prioritize the provision of protective equipment to LTC staff, since they were not categorized as health workers (Nyashanu, Pfende and Ekpenyong, 2020).

These experiences have prompted calls for a deep or “structural” integration of health and care services for older people, to become parts of a single system (Harvey et al., 2018; Lloyd- Sherlock et al., 2019). In recognition, most high-income countries have embraced integration of some sort, albeit with mixed results (The Kings Fund, 2018). More superficial and cosmetic forms of integration have been relatively easily implemented. For example, in 2018, the United Kingdom’s Department of Health was renamed the Department of Health and Social Care, and this was shortly followed by a new plan for service integration (National Audit Office, 2019). However, merging institutional structures that had developed independently over decades has proven a very challenging agenda (The Kings Fund, 2018). There is growing awareness that effective integration requires fundamental changes to models of training, provision, and professional behavior and must resolve multiple, deep-rooted professional, cultural, and institutional disconnects across health care and LTC. Low and middle-income countries could benefit from these lessons while their services for older people are at earlier stages of development.

Interventions to support care-dependent older people living in the community.

This report describes and presents findings of evaluations of an intervention which has been operating in the Brazilian city of Belo Horizonte since 2011: Programa Maior Cuidado (PMC). Section 1 of this report provides a detailed description of PMC. Key features include:

- √ Joint operation by the municipal Department of Health (DoH) and Department of Social Assistance (DoSA).
- √ A focus on dependent older people living in vulnerable families in deprived neighbourhoods.
- √ Families receive up to 20 hours of support a week from professional family care support workers.
- √ Between 2011 and December 2022, 3,062 families had received support or were continuing to do so.
- √ Health centres and social assistance posts work closely with family care support workers, including joint monthly case reviews of older people included in the programme.

PMC shares some similarities with interventions elsewhere in Latin America and the Caribbean and high-income countries but is unique in two specific ways.

a) Programa Maior Cuidado is deeply intersectoral.

In high-income countries, almost all interventions to provide home care for older people are operated separately by social assistance agencies[6] (such as visits by care workers to assist with daily activities) or by health agencies (such as periodic visits by multi-disciplinary health teams) (Rytter et al, 2010; Wan, Mitchell and Maier, 2021). In Latin America and the Caribbean, a similar division can be observed. Examples of the former include Uruguay's Programa de Assistentes Personales (División de Evaluación, 2020). Examples of schemes operated solely by health agencies include the Programa Acompanhante de Idosos (PAI) in São Paulo city, Brazil (Andrade et al, 2020; Peroni et al, 2023). PMC is different, in that it is genuinely intersectoral.[7] This report will examine how this inter-sectoral collaboration works in practice and will assess its effect.

[6] In high-income countries, social assistance is more commonly referred to as social services or social work. We use the term social assistance to cover all these labels.

[7] Intersectorality is defined as a collaborative approach, spanning across various ministries, government agencies, nongovernmental organizations and other groups, with a common goal of addressing a particular issue (Amri, Chatur & O'Campo, 2022). In this report, we define "deep intersectorality" as a high degree of collaboration, in which partner organisations play a substantial role. This should not be confused with multidisciplinary interventions, which include diverse sets of professionals, but only from one government body, or with integrated healthcare, which usually refers to linkages between different components of the health system.

b) Programa Maior Cuidado's family care support workers represent a new category of family care support professional.

Across low and middle-income countries, there are increasing numbers of people working in paid elder care, both through the private sector and through different government schemes (Waisgrais et al, 2018). These workers receive various levels of training and supervision. Uniquely in PMC, these workers are fully integrated into local health and social assistance teams, both in terms of receiving support and providing updates on the status of the older person and their family.

These two aspects of PMC set it apart from other interventions. The key objective of this report is to assess whether they work well in practice and how they affect the lives of vulnerable care-dependent older people and their families.

The report is structured as follows. Section 1 provides a detailed description of PMC and the context in which it operates. Section 2 evaluates how effectively PMC functions in practice. Section 3 evaluates effects of PMC on older people, their families and the people it employs as Family care support workers. Section 4 evaluates the effects of PMC on health service use by older people. Section 5 presents an analysis of costs and benefits. Section 6 assesses the potential for learning from PMC in other cities. Section 7 sets out key lessons and areas for further research.

Section 1. Programa Maior Cuidado. Context and key features.

Health and social assistance services in Brazil.

Compared to other low and middle-income countries, Brazil has an embracing and well-developed health service infrastructure, centred on the Unified National Health System (Sistema Único de Saúde – SUS). SUS is mainly managed by municipal governments and includes a strong focus on community-based primary health care (Macinko and Harris, 2015). Family Health Teams are responsible for referral and coordinating across SUS services, as well as acting as a bridge between the health system and local communities. The institutional hub for this service is the Community Health Centre (Unidade Básica de Saúde, UBS).

Brazil also has a National System of Social Assistance (SUAS) that is structured along broadly similar lines to the SUS, albeit with fewer resources or reach. The main focus of SUAS is social inclusion by managing the provision of non-contributory benefits, including a social assistance pension, the Benefício de Prestação Continuada (BPC). It is also responsible for a diverse set of social service and social work programmes for vulnerable population groups, including older people living in poor neighbourhoods. As with SUS, SUAS has a highly decentralized management structure, with services provided in deprived neighbourhoods through community Social Assistance Reference Centres (CRAS) and more specialized community Social Assistance Specialised Reference Centres (CREAS) (Borges, 2012). The CRAS do not cover every rural or urban district in Brazil: instead, they are mainly located in areas considered to be relatively deprived.

The rationale for developing an integrated community-based intervention for care-dependent older people in Belo Horizonte.

The development of PMC in Belo Horizonte and the particular design it takes reflected a number of concerns shared by policymakers in the city government. As in other parts of Brazil, there were fast-growing numbers of older people with care needs, including in poor neighbourhoods. The total number of LTC facilities in the city had reached 77 by 2010[8], but policymakers doubted the capacity and suitability of LTC facilities to meet their city's growing need. Also, they were aware of quality issues with some LTC facilities and of older people's preference to remain at home. There was growing recognition of the challenging and demanding nature of family caregiving for older people, and that family carers deserved and required support.

Policymakers were also concerned about the rising costs of health services for older people. Nationally, by 2015 people aged 60 or more accounted for 39 per cent of the total adult inpatient budget of public hospitals (Dias and de Barros, 2019). As in other countries, there was recognition that many hospital admissions could be avoided were suitable services available in the community

[8] By 2020, the number of LTC facilities in Belo Horizonte had increased to 230.

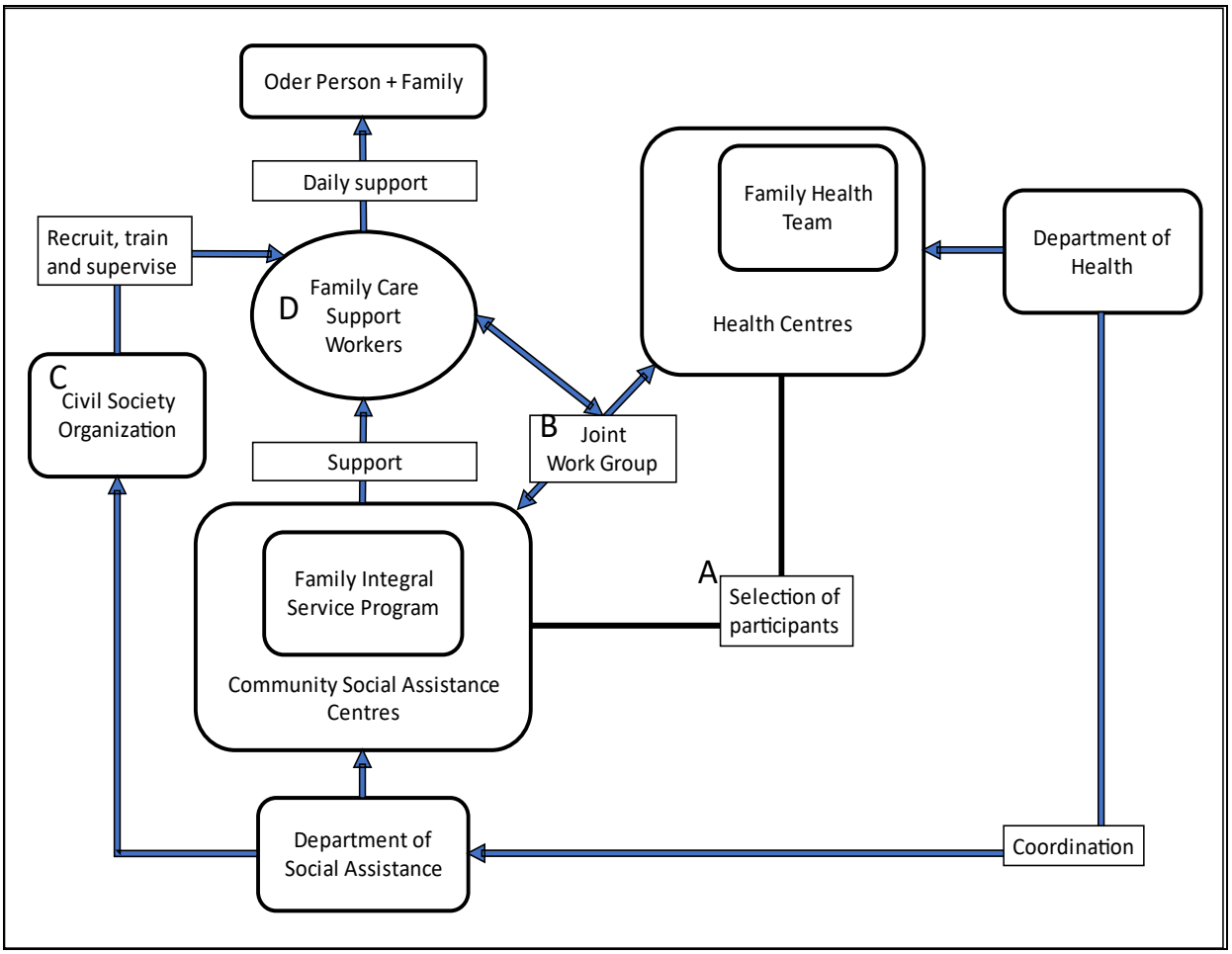
(Lloyd-Sherlock et al., 2020). The leading causes of admissions for older people in Brazil are urinary tract infections, falls, and poor management of chronic conditions: much of which could be averted through effective home care. It has been calculated that 31 per cent of inpatient hospital spending on people aged 60 or over in Brazil's National Health System between 2000 and 2013 was for conditions more suited to ambulatory treatment (de Souza and Peixoto, 2017).

In some high-income countries, cash payments for either dependent older people or for unpaid caregivers have become an important element of LTC systems (Doty, 2023). However, the prevailing view among policymakers in Department of Health and Department of Social Assistance was that cash transfer schemes were not an optimal policy response. Experience with targeted cash transfer schemes for people with disabilities shows that targeting is usually an expensive and imperfect process, especially if it includes a care needs assessment (Mishra and Kar, 2017). Also, there were doubts about the extent to which families had sufficient knowledge about LTC to make informed decisions about purchasing care. A further concern was that, in contexts of income poverty, care payments might be appropriated by other family members for their own use. Research shows financial abuse of older people is prevalent in Latin America and the Caribbean, and that there is a strong correlation between dependency and the risk of financial abuse (Giraldo-Rodríguez, Rosas-Carrasco and Mino-León, 2015; Johannesen and Lo Giudice, 2013). Specifically in Brazil, relatives of older people have sometimes taken advantage of low-interest loans secured against pensions, leaving the older person with large debts (Santos, 2018).

The structure and operation of PMC.

From the outset, the PMC has had a number of unusual but significant features. It was developed jointly by DoH and DoSA, and they continue to run it in partnership. This inter-sectoral approach is unique in Latin America, where there is usually a high degree of service fragmentation and an abrupt disconnect between health and social care.

Figure 1.1 - Main components of Programa Maior Cuidado



Source: Authors.

Figure 1.1 presents the main elements of PMC and the relationships between them, and highlights four critical components of the scheme, labelled A, B, C and D.

A: Screening of potential participants.

A key PMC philosophy is to consider the wider circumstances of older people and their families, not just the older person's health and functional status. This is especially relevant in the communities where PMC operates, where many families are facing multiple problems and deprivations. Their difficult circumstances affect the chances that older people will get good quality care at home and require support from social assistants as well as health workers. Most older people referred to PMC have recently been in hospital or have experienced an acute health episode. Usually, they are initially identified by members of local social assistance or primary health care teams. PMC has a number of specific inclusion criteria, including being aged 60 or over, living in a district corresponding to a specific Social Assistance Reference Centre and being registered with the local health centre and the federal Unified Register of Social Programs (Cadastro Único). A nurse and social worker make a home visit to apply a standardised screening

tool (Appendix 1). This covers the older person's health and functional status, as well as risk factors for emergency health service use, such as frequent falls, and uncontrolled hypertension or diabetes. The decision to include the older person in PMC depends on the availability of a place and the level of assessed need, as well as the consent of the older person and their family. When PMC lacks the capacity to take on new cases, they are put on a structured waiting list (Appendix 2).

B: Joint working groups.

Members of local family health and social assistance teams meet monthly to prioritize new potential PMC participants and to review existing cases. Working group membership typically comprises of nurses, social assistants, and community health workers.

C: Civil Society Organization.

This organization is paid by the Municipality of Belo Horizonte to perform a number of roles, including the recruitment, training and supervision of family care support workers (FCWs).

D: Family Care Support Workers (FCSW).

Families participating in PMC receive support from trained family care support workers, who are paid a basic wage and recruited from similar communities. FCSWs work 40 hours a week, caring for between one and three families. Each family receives between 10 and 20 hours of care support a week, depending on the level of need of the older person and the family's wider situation. FCSWs wear a uniform and are jointly supervised by staff from the local UBS and CRAS. Specific roles and duties for PMC carers include supporting family caregiving and a limited set of clinical responsibilities (Table 1.1). FCSWs feed into monitoring reports (Appendix 3) which are discussed in the monthly case reviews.

FCSWs are not expected to completely replace family care responsibility for dependent relatives. Instead, the focus is on providing families some respite from what an exhausting 24/7 activity is often. At the same time, FCSWs are expected to work with family members to build their own care skills and competence. Together with the older person, the FCSW and family agree a personal care plan that seeks to involve all household members (Appendix 4). As well as providing daily support, FCSWs monitor the situation of the older person and report back to the joint monthly case reviews.

Table 1.1 - Selected roles and duties of Family Care Support Workers.

Family care support.	**Health duties.**	**Interaction with CRAS, UBS and monthly case reviews.**
- Follow the personal care plan agreed with the Social Assistance Reference Centre and local health team. - Guide the family's organization of care for the older person. - Prepare food for the older person, in accordance with the personal care plan. - Assist with bathing the older person, in accordance with the personal care plan. - Identify potential modifications to the home environment to reflect the older person's needs.	- Provide cognitive stimulation and occupational therapy. - Assist in physical exercises recommended by the local health team. - Manage the older person's medications, only administering those which have been prescribed by a health professional. - Do not administer non-prescribed medication including traditional remedies. - Do not perform specialist nursing tasks, such as providing injections or measuring blood pressure. - Pay attention to physical or emotional changes in the older person and inform the local health team. - Assist and supervise the nutrition and hydration of the older person, as well as continence. - Inform the health team of significant changes to stools or urine. - Accompany the older person on visits to hospitals and clinics, as needed. - Follow public health guidance to reduce risk of infection of COVID-19 or other respiratory diseases.	- Participate in monthly case review meetings. - Provide monthly updates on the status of the older person to Social Assistance Reference Centre and local health team. - Discuss personal care plans, including modifications to them, with Social Assistance Reference Centre and local health team. - Immediately inform supervisor of emergency situations that put either the older person or their caregivers at risk. - Participate in ongoing training and capacity-building programs.

Source: Authors.

Section 2. Review of PMC's operational effectiveness.

Between 2018 and 2022 there has been an ongoing operational process review of PMC. This has included three distinct elements (Table 2.1). The first consisted of the evaluation team's "deep dive" familiarization with PMC. The second element of the review occurred opportunistically, during the COVID-19 pandemic. This represents a "stress-test" of PMC's operation under highly challenging conditions. The third element assessed changes to PMC implemented in response to findings of the first element of the operational review.

Table 2.1 - Elements of operational process review.

Element	Objective	Timing
Element 1	Initial deep dive and process evaluation.	December 2018 to October 2019
Element 2	COVID-19 stress test.	May to September 2021
Element 3	Process evaluation of reform implementation.	March to December 2022

Source: Authors.

Element 1. Initial deep dive and process evaluation.

Element 1 drew on the following sources of information:

- ✓ A review of documents belonging to Department of Health and Department of Social Assistance, including PMC screening and monitoring protocols, care plan guidance and family care support worker protocols.
- ✓ Participant observation of meetings (n = 20) and focus group discussions with key informants (n= 7 with 51 participants), including nurses, social workers, nutritionists, and psychologists, who were involved in either management or the daily operation of PMC.
- ✓ Records for all 3,062 older people who participated in PMC from its commencement until the end of 2022. These include data on age, sex, address, level of care dependency, date of inclusion in PMC and date of leaving and reason (Table 2.2).
- ✓ Longitudinal observation of two joint working groups, over several months.

The availability of reliable records on participants and the willingness of Department of Health and Department of Social Assistance to share them with the independent evaluation team are themselves important indications of PMC effective operation. Table 2.2 shows that over half of older people who had participated in PMC were aged 80 or more when they joined, 70 per cent were female and 42 per cent had a high level of dependency. On average older people remained in PMC for 21 months. The most frequent reason for leaving PMC was the death of the older person (49 per cent of cases), which demonstrates that PMC continued to support many older

people and their carers until the very end. In 10 per cent of cases, families felt they were able to resume taking full care responsibility, reflecting an increased level of capacity, competency, and confidence in performing this role. The number of older people who left PMC because they were admitted to a LTC facility was under 6 per cent.

Table 2.2. Data on PMC participants derived from monitoring records, 2011 to 2022.

Parameter	Participants	
	Active members N (%)	Disconnected from PMC N (%)
Age when joined		
60 to 69 years	151 (24,4)	466 (19,1)
70 to 79 years	215 (34,7)	801 (32,9)
80 to 89 years	190 (30,6)	846 (34,7)
90 years +	64 (10,3)	325 (13,3)
Gender		
Female	431 (69,5)	1662 (68,1)
Male	189 (30,5)	780 (31,9)
Level of care dependency		
Dependent	260 (41,9)	1095 (44,8)
Semi dependent	360 (58,1)	1347 (55,2)
Average length of stay in program (months)	29	21*
Reason for leaving		
Transfer to LTC facility	-	145 (5,9)
Risk situation for the caregiver	-	97 (4,0)
Older person refusal	-	135 (5,5)
Rehabilitation of the older person	-	86 (3,5)
Family Option	-	244 (10,0)
Death	-	1207 (49,4)
Change of territory	-	147 (6,0)
Change of municipality	-	97 (4,0)
Family referred to different social service agency	-	36 (1,5)
Family resumes care	-	248 (10,2)

*19 cases without code. Source: Authors.

Key findings of Element 1 include:

Strengths:

- ✓ There was a good overall level of operational fidelity. Processes set out in principle usually matched the evaluation team's observations of actual practice. The screening tool was applied appropriately. Monthly work groups followed the correct procedures and family care support workers operated effectively.
- ✓ There were very good levels of buy-in and support for PMC among all stakeholders involved in management and practice. Participants in all focus groups were asked to describe what PMC meant to them with a single word, which could be positive, negative, or neutral. These words were entered into Wordle31, which created the algorithm presented in Figure 2.1. All participants selected positive words reflecting their belief in PMC's positive effects.
- ✓ Interviews and observations with stakeholders reveal a high level of willingness to collaborate across DoH and DoSA, notwithstanding some bureaucratic barriers and disconnects in data systems.
- ✓ There was a good level of operational consistency between the CRAS and UBSs, as well as over time. PMC operational processes remained consistent between 2011 and 2023, despite four changes of city government.

Figure 2.1 Programa Maior Cuidado in one word.

Source: Lloyd-Sherlock, Aredes et al (2019).

Areas for improvement:

- There were few official documents on PMC's formal institutional status, management guidelines or protocols.
- PMC operated on an ad hoc set of agreements between health and social assistance professionals, but these were not supported by a formal institutional structure. This sometimes led to confusion about each department's specific roles and responsibilities, and to small variations in practice between different CRAS and UBSs.
- Combined monitoring and data sharing across DoH and DoSA were hampered by a lack of compatibility between their respective wider information systems.
- Stakeholders observed that PMC's coverage was low in relation to need, giving rise to waiting lists of older people who were eligible for inclusion. Coverage was also limited because PMC did not operate in all CRASs in Belo Horizonte.

Element 2. Covid-19 stress test.

The first cases of COVID-19 in Belo Horizonte were reported on 8 March 2020, shortly after completion of the initial operational evaluation. Like other cities in Brazil, rates of infection were very high in deprived neighbourhoods and older people were at particular risk of COVID-19 mortality. It was therefore anticipated that the pandemic would substantively affect the operation of PMC and that rapid adaptation would be necessary. Consequently, the research team developed a survey distributed by email to managers responsible for all 36 CRAS/UBSs where PMC was operating. The questionnaire and results of this stress test study are presented in Annex 1. They show that home visits were temporarily suspended and replaced, in most cases, by regular telephone support calls. Visits were resumed once lockdown restrictions permitted them. Because family care support workers were not officially categorized as "health professionals", they did not receive the same priority access to personal protective equipment and, later, to vaccinations as other frontline health workers. This is an example of the need for stronger intersectoral recognition of FCSWs' status and role.

Element 3. Process evaluation of reform implementation.

In late 2019 the findings of the first phase of the evaluation were shared with senior managers from the DoH and DoSA, as well as other stakeholders. On the basis of these findings, DoH and DoSA agreed to carry out reforms to PMC's operational and information systems. These included the first ever formal legal agreement between these two departments, the development of a joint operational protocol manual and a new shared referral and information system. Among other advances, these reforms established key areas of competency for the different agencies involved in the day-to-day operation of PMC (Table 2.3).

During 2023 DoH and DoSA started to jointly develop and pilot a systematic, comprehensive information and monitoring system. This system will include regular updates on the health and wellbeing of older participants in PMC, as well as risk factors and information about other family issues potentially affecting the quality of care. It is proposed that this information will be collected by family care support workers, shared with the monthly case reviews and collated at the program level. As of July 2023, piloting was ongoing, and it remained unclear when and in what form the new information system would be universally adopted.

The broadly positive results of the initial process evaluation contributed to a decision, taken in 2019, to extend PMC, to cover every CRAS in Belo Horizonte. According to some key informants, the process of extending PMC across Belo Horizonte was unproblematic (Q2.1). However, some staff noted that this coincided with the onset of Wave 1 of the COVID-19 pandemic, which was already putting existing services under strain (Q2.2). Nonetheless, PMC was successfully installed in all these Social Assistance Reference Centres, and this was validated by the evaluation team which observed a joint work group in one of the newly included CRASs.

> Q2.1. *It was a smooth process. There were eight Social Assistance Reference Centres that needed to be included in the program. We had been contacted by our management and had started to receive training from the beginning of December… So we were already well organized when it was time to start implementing PMC. The health centre already had a long waiting list, so we listed the priority cases for inclusion. We didn't experience any problems, either in the implementation process or in working with the families.* (E19, Social Worker, Social Assistance Reference Centre)

> Q2.2. *We worked face-to-face with PMC managers for three months, in December, January and February. PMC was initiated in our Social Assistance Reference Centre at a time of great difficulty. We only had two professional staff to manage PMC, along with all our other social programs.* (E18, F, Social Worker, Social Assistance Reference Centre).

Table 2.3. Key competencies of different agencies involved in PMC.

Department of Social Assistance	Department of Health	Civil Society Organization
Manage aspects of PMC related to social protection issues. Provide guidance for CRAS staff for identification and follow-up of families with vulnerable older people. Program monitoring and evaluation. Coordinate with DoH. Supervise and monitor the partner Civil Society Organization. Train family care support workers and supervisors, in partnership with DoH and the Civil Society Organization. Elaborate documents and instruments. Coordinate with social assistance agencies at the state and national levels.	Manage aspects of PMC related to health issues. Program monitoring and evaluation. Coordinate with DoSA. Train family care support workers and supervisors, in partnership with DoSA and the Civil Society Organization. Elaborate documents and instruments. Coordinate with health agencies at the state and national levels.	Select, hire, and monitor family care support workers and supervisors. Train family care support workers in partnership with DoH and DoSA. Provide accountable financial reporting to the municipal government. Maintain a legal partnership status with the municipality. Ensure quality standards for actions provided in the partnership. Provide food and transportation vouchers for family care support workers. Participate in meetings with DoH and DoSA.

Source: Authors

Section 3. The effects of Programa Maior Cuidado on older people, their families and on family care support workers.

PMC and older people.

Older people eligible to be included in PMC are by definition poor, either moderately or highly care-dependent, live in vulnerable families and are affected by serious chronic health conditions. As noted in Section 2, coverage of PMC is low relative to levels of need in the neighbourhoods where it operates. The screening tool enables PMC staff to prioritize those people who face the greatest need.

Reflecting this participant profile, it is not realistic to expect PMC will significantly reduce care dependency or function as a curative intervention. Instead, it seeks to optimise the health, functional status, and wellbeing of older people, during what are almost always the last few months or years of their lives. Rather than whether or not PMC reverses the decline and the associated suffering experienced by older people, the more salient question is whether PMC reduces the rate of decline and mitigates its effects. Longitudinal comparisons between paired sets of older people enrolled in PMC and control groups could potentially capture these effects, but it was not feasible to create controls for the purpose of our evaluation. Despite this, it is still possible to obtain insights about these potential effects from qualitative data.

Health benefits for older people.

Although family care support workers are not defined as health professionals, they have a set of skills and competencies that can directly and indirectly enhance the health status of care-dependent older people. For example, family care support workers usually assist older people to manage chronic health conditions which might otherwise lead to emergency health service needs. (Q3.1 and Q3.2).

> Q3.1. *In terms of things like, medication, food, hygiene and even basic care, we see improvements in health of many older people after they join PMC.* (E4, F, Speech therapist, UBS)

> Q3.2. *When the carer is there, he really looks after the older person's hygiene and the administration and management of their medication. But it's also an opportunity to play memory games or to talk about any problems in the home environment. The older man told me that he has resumed some activities he enjoys and that now he has someone to talk to.* (E10, F, Social Worker, CRAS)

Chronic health management often overlaps with preventing risk factors and providing more general forms of care. This was especially evident in areas such as hygiene and hydration (Q3.3).

> Q3.3. *When I get there, she's in bed and her incontinence pad usually ends up leaking. As a PMC carer, I change the bed sheets… bathe her… make sure she's clean and*

hygienic. Then I put on a fresh pad for her. While we have breakfast together, I make sure she takes her meds. After that we do some physiotherapy exercises -I was given a set for her by the physio here at the health post. (I28, F, Family care support worker)

This also included reducing the risk of falls, such as by modifying the home environment (Q3.4).

Q3.4. *They used to have a bathmat that was always slipping. I had been warned about this in my training, and so I said that, if they didn't mind, could they remove the mat because their sister is so weak, she could easily trip on it. And they were happy to get rid of it.* (I28, F, Family care support worker)

Family care support workers do not operate in isolation, sharing information with and collaborating with health and social assistance professionals (Q3.5, Q3.6, Q3.7).

Q3.5. *Older people often develop a close bond with their family care support workers. This means that they sometimes share information with this person that they would avoid mentioning to a doctor. This really helps the people in the health centre to ensure they are OK.* (I46, F, Nurse, Family Health Team)

Q3.6. *Older people included in PMC are so much better attended to and have much better contact with the health services. Every month the family care support workers inform us about what is needed, based on what they see during their visits. They start to understand how caregiving and health relate to each other. Then, the review team follows up as best we can. It might be a general consultation or a referral to a specialist, a dietician, or a physio.* (I7, F, Nurse, Family Health Team)

Q3.7. *The social assistance worker and family care support workers reassess their parts of the personal care plans, and the parts that are more to do with health are reviewed by the health post. When it's possible, the PMC carers can suggest changes to care plans at the monthly case reviews. They take a close interest in that.* (I40, M, Social Worker, CRAS)

One effect limiting the impact of PMC on the health of older people is the availability of higher-level health services, when they are needed. Liaison between the family care support workers and the health post can facilitate older people receiving a referral when needed, but this does not give people in PMC a higher referral priority over those who are not. A wider context of scarce health resources often means long wait for urgent health services (Q3.8).

Q3.8. *Sometimes an older person hasn't had a diagnosis. You know what they have, but you can't tell them, you can't do anything. You just have to wait for the diagnosis, so the doctor can tell the family what is going on.* (I28, F, Family care support worker)

Wellbeing and quality of life of older people.

PMC's approach to supporting older people recognizes that health, quality of life and wellbeing are all closely linked. Unlike other home-visit schemes, PMC offers each older person a substantial period of care each week. This enables family care support workers to build trusting relationships with the older person, and to provide activities such as cognitive stimulation and physiotherapy (Q3.9 and Q3.10).

> Q3.9. *We offer stimulation for older people and sometimes this even leads to an improvement in their function. The time the caregiver spends with them is so important, not just in terms of improving function, but also for emotional support and cognitive stimulation.* (E6, F, Physiotherapist, Extended Family Health Team)

> Q3.10. *The family is calmer and so the older person feels safer. Family care support workers help in dealing with emotional issues, aging, sometimes isolation, and sometimes abandonment by the family. When the children are not managing to deal with this aging process, with the illnesses. And so it is really a big support, both for physical and mental health. The older person feels seen, accompanied let's say. It's a source of company: someone who talks to you and who stimulates you. So, I think both physically and emotionally this all adds up.* (E3, F, Nurse, UBS)

As part of a person-centred care strategy, family care support workers are encouraged to discover activities that older people enjoy doing and to assist them with these (Q3.11).

> Q3.11. *There are many examples of this happening. There is an older woman who learned to read with her caregiver. Think about what this means for this older woman's life! It can transform the quality of life for these older people.* (E16, F, Psychologist, CRAS)

More generally, family care support workers seek to address issues such as loneliness and isolation, guaranteeing a substantial period each week when the older person will be listened to, and their interests and concerns acknowledged. One limiting factor was the practice of rotating family care support workers between families approximately every year. Rotation was seen by PMC managers as necessary to prevent FCSWs developing such close bonds with older people and their families, since this could interfere with their professional status. Understandably, some older people felt that changing FCSWs disrupted valuable social ties (Q3.12).

> Q3.12. *"My first PMC carer stayed with me for a year and four months. I adored her. There will never be another carer like her [cries]".* (92-year-old man) [Field report].

In sum, the extent and strength of the qualitative evidence indicates that PMC generates important benefits for the health status, wellbeing, and quality of life of older people. There is a large body of research demonstrating that most older people prefer to remain in their own homes, especially if they are able to receive support there (WHO, 2015). As shown in Section 3, only a small number of older people enrolled in PMC are subsequently admitted into LTC facilities: this represents a further benefit to their quality of life.

PMC and Families.

Older people eligible for inclusion in PMC have moderate or severe care needs and live in households that are unable to afford private care services. In Belo Horizonte in May 2023, the market rate for a caregiver with a similar level of training and experience was around US$60 for 15 hours of care a week (a typical amount offered by PMC). This amount is equivalent to approximately 95 per cent of the basic Benefício de Prestação Continuada pension (US$66.5 a week) and would therefore leave no income for other basic needs for the older person. There is a large body of evidence that other members of poor households often have a high level of dependency on the pension income of older people, which further reduces the availability of disposable income to pay for care services (Barrientos and Lloyd-Sherlock, 2011).

In the neighbourhoods where it operates, other than PMC, no free services to support family caring, such as day centres, are available[9]. If they are not included in PMC, the entire care responsibility therefore falls on family members. There is a large body of evidence from Brazil and similar countries demonstrating the stressful and demanding nature of unsupported family care for dependent older people and the toll it can take on those providing it (Leite et al, 2017). Studies demonstrate that the care burden in Brazil is higher for carers in poor families (Magalhães, et al 2022).

PMC's screening tool includes several items related to the care burden experienced by family carers, and these are given a significant weighting (11 out of 60 points).10 However, PMC does not collect systematic data on changes to this burden over time, and so it was not possible to include this in the quantitative evaluation. Nevertheless, it is highly likely that receiving substantial hours of support from a family care support worker will significantly reduce this burden for family members. There is substantial evidence from other studies that family carers often have few breaks from this activity and that guaranteed periods of respite significantly mitigate care burden (Gaugler et al, 2003). Qualitative data collected for the PMC evaluation strongly indicate this effect (Q3.13, Q3.14 and Q3.15).

> Q3.13. *It reduces family caregivers' overload, meaning these caregivers can now do important things that they just couldn't do before. Many of these family caregivers actually become closer to the older person. Reducing their care burden, sharing it and being able to talk about it with someone else means they can get to know the older person again.* (E6, F, Physiotherapist, Extended Family Health Team)

> Q3.14. *Something I feel to be very important is the sharing of tasks. Before PMC, the caregiver is overwhelmed, doing all the housework, and providing all the older person's care without any help. With PMC, the caregiver has time to organize themself better and take better care of themself. This reduces their mental stress. PMC is good for caregivers. They can see the possibility of making plans to do things that they hadn't done for a long*

[9] Belo Horizonte does not have public day centres for older people.
[10] Care burden usually refers to financial, physical and psychological effects of unpaid caring and is widely applied globally and in Brazil (Gratão et al, 2019).

time due to lack of time. (E19, F, Social Assistant, CRAS)

Q3.15. *When you start to work with a family, the caregiver is so stressed out, because there usually is only one person in each family who does the main care work. They have no life. Sometimes they can't even manage to visit a health centre when they are unwell. So, when we put in a PMC caregiver, it's transformational.* (E17, F, Psychologist, CRAS)

Wider research in Brazil demonstrates that a significant share of unpaid family elder care is provided by older people themselves, often caring for spouses, and that care burden increases with the age of the carer (Bianchi et al, 2016). In the PMC screening tool, families are given more points if the main carer is an older person. As part of reducing this burden, the qualitative data indicate important health benefits for older carers (Q3.16).

Q3.16 *In many families, the family caregiver is older person… And they are starting to get ill, because they can't take care of their own health, because they can't leave the older person alone. So, PMC helps them a lot. Many caregivers are worn out and stressed when they join the program, but then they can start to take care of their own health, get their hair cut, do their nails, buy personal things. This really helps these families. Many family caregivers schedule their own medical visits, appointments, consultations or collecting medication for when the PMC carer is at their home.* (E7, F, Nurse, UBS)

The qualitative data indicate that the relationship between the family care support workers and the main family carer is just as important as that between the family care support workers and the dependent older person. Rather than replacing the family carer, this relationship is better understood as a collaborative partnership (Q3.17).

Q3.17. *"Persuading her to take a shower is very complicated, because she gets very aggressive. She wants to hit out, she wants to bite. So, I always need the help of her daughter. Once she's in the bath, she usually calms down."* (E25, F, Family care support worker)

Family carers have the opportunity to work with, observe and learn from family care support workers, potentially increasing their competency and confidence to perform this role (Q3.18). One limiting effect is that the identity of the family member providing the main care role can change (Q3.19).

Q3.18. *"We try to prevent situations that entail a violation of older people's rights. The make suggestions to family members…. These include simple things like help with drinking by using a straw. This does not create extra work for the family.*" (E23, F, Psychologist and Social Worker, CRAS)

Q3.19. *This [caring for older person] is a massive responsibility and I've got absolutely no experience. It's the first time I've had to do this, having to take responsibility for everything.* (Younger family member, F, after the death of father who had been mother's main carer)

PMC works with vulnerable families, and the screening tool awards points to issues such as family conflict, mental illness, and additions. Developing effective partnerships with family carers in these

settings is often highly challenging and requires sensitivity and patience (Q3.20 and Q3.21).

> Q3.20. *Recently a family member with a severe mental disorder… just stopped the family care support workers from leaving the house. They locked them in.* (Social Assistant, Northern Regional Health District, 2019)

> Q3.21. *Sometimes family carers don't really understand the role or function of the PMC carers. Sometimes they complain that the family care support workers aren't doing general housework; things like 'The sink was full of dirty dishes and they didn't touch them' or 'I had to cook my own lunch.* (Nurse, Central-South Regional Health District, 2019)

Being jointly run between health and social care professionals, PMC is well-placed to deal with these challenging family situations. Responses include support meetings with families which can sometimes reduce family problems (Q3.22).

> Q3.22. *The family care support workers' presence in the house can help families a lot. It can defuse family conflicts. Family care support workers' knowledge of the family helps us to identify other social assistance programmes that may be of help to them. We try to hold two annual meetings with all the family together… Families say that this really helps them in different ways.* (E12, F, Psychologist, CRAS)

There is a large body of evidence that high carer burden and family tension significantly worsen care outcomes and quality of life of older family members and are strongly associated with the risk of elder abuse (Lino et al., 2019). There is also evidence that family carer stress (along with poverty and a lack of external support) is an important risk factor for elder abuse in community settings (Johannesen and Lo Guidice, 2013). Although the impact evaluations of PMC did not specifically address issues of elder abuse, there are good grounds for hypothesizing it has an important preventive effect. If so, it represents a different approach to elder abuse than the ones usually applied in Latin America which focus on dealing with the problem after it has occurred, rather than preventing it. The ethical and methodological challenges of robustly assessing the potential effect of PMC on elder abuse call for a specific, customized study.

PMC and family care support workers.

Family care support workers represent a new category of health and social care professional. They are usually recruited from disadvantaged communities and most, but not all, are female. As such a critical question is whether this new profession is an extension of the low-status, mainly female paid care work that prevails across Latin America and the Caribbean, or if it empowers family care support workers.

Recruitment, training, deployment, and supervision of family care support workers are the responsibility of a civil society organization, which holds a contract with the Department of Social Assistance. The civil society organization advertises training opportunities and applicants are interviewed. They are required to have completed secondary school and demonstrate a basic

level of understanding about caregiving for older people. The civil society organization recruit people living in neighbourhoods not distant from where PMC operates. The selection interview includes a particular emphasis on candidates' sensitivity towards and willingness to work with challenging families in difficult circumstances.

Candidates who are selected are provided training with two elements. The first of these is a general care-giving course, consisting of 100 hours, which includes training about common health issues affecting older people, as well as care-giving skills and supporting family carers. If candidates can demonstrate they already have had similar training from another organization, they are exempt from this course. All candidates, regardless of previous training, are required to take a separate two-day induction course for PMC. This course provides specific information about PMC and their expected role. It also includes specific training on how to deal with challenging family situations in settings of poverty and deprivation.

Family care support workers' previous experiences often includes paid or unpaid care and precarious forms of employment (Q3.23).

> Q3.23. *It's been about 7 years since I first became a caregiver. My father fell ill and I saw he needed care and wanted some help. So, I took a training course and learned how to do it. I took care of him, then I looked after an aunt and after that a sister-in-law. I also worked for 4 years at a nursing home.* (E26, F, family care support worker)

Some other schemes offering home care for older people in countries such as Costa Rica and Thailand rely on volunteers rather than paid carers (Lloyd-Sherlock et al, 2017). As a result, they experience low levels of worker retention and limited professionalism. In contrast, PMC provides family care support workers with a basic wage and full labour protection rights. Given a general scarcity of decent work opportunities for women in poor neighbourhoods, this represents an important livelihood opportunity (Q3.24).

> Q3.24. *I thank you for the opportunity to talk a little about my work and the program that has helped so many families and mine too, I take my livelihood home with this work.* (E29, F, Family care support worker)

As part of their professional status, family care support workers work a 40-hour week, with full holiday entitlements and wear a simple uniform. Their professional status extends to the development of some complex and specific care-giving skills (Q3.25). After their initial training, family care support workers can request and are offered focused training modules, in areas such as cognitive stimulation and managing incontinence.

> Q3.25. *The PMC carers are sometimes trained in specific tasks, like administering insulin, by the local health post, and the physiotherapist will show them particular exercises for their patients.* (I12, F, Psychologist, CRAS)

Family care support workers are embedded within wider teams of health and social assistance professionals and can play a proactive role in them (Q3.26 and Q3.27), even during Covid-19.

> Q3.26. *They identify new needs and then pass them on to us or their supervisors, so we*

can raise them in the monthly meetings. Now we are trying to involve them more closely, creating a space for them to participate in meetings in the Social Assistance Reference Centre. It is different when they participate in person. (E01, F, Family care support worker)

Q3.27. *I can see they are very motivated by work. They are always seeking to improve what they do and to find interesting activities, like new games, drawing and different types of crafts* (E02, F, Psychologist, Extended Family Health Team)

Family care support workers appear to value their professional status and the opportunity to develop new skills (Q3.28 and Q3.29).

Q3.28. *We learn and at the same time we are able to teach the families. It adds a lot to our lives and as well to theirs.* (E28, F, Family care support worker)

Q3.29. *Many tell us they did not previously have any experience with deprived parts of the city. Now they know more about their rights and social assistance policy. Many of them did not even know what Social Assistance Reference Centres were for before they started to work with PMC.* (E12, F, Psychologist, CRAS)

As well as specific care-giving skills, key informants claimed that family care support workers quickly learn to work effectively with vulnerable families that are often facing complex problems (Q3.30).

Q3.30. *Most of our family care support workers are very happy. But sometimes when they first enter a home the family can be difficult, and so they have problems accessing the older person. Sometimes the older person can be resistant to family care support workers at first. But when the family care support workers return day after day, they build trust with the family and learn to work with them. Each achievement with the older person really motivates our family care support workers.* (E7, F, Nurse, Extended Family Health Team)

Recognizing the challenging nature of this role, PMC provides family care support workers with specific forms of support (Q3.31).

Q3.31. *We had a successful experience in a local working group in this district. A psychologist met privately with our caregivers before the meeting, to offer them some support. Caregivers also need care. They experience a very tough reality... Drugs, mistreatment, neglect, violence. They need a voice too.* (E12, F, Psychologist, CRAS)

As a condition of working in PMC, family care support workers are required to sign a code of conduct, which includes standards of behaviour, confidentiality requirements and action protocols for suspected cases of abuse of the older person or other forms of observed criminality.

Section 4. PMC effects on health service use by older people.

Section 1 notes that high levels of health service spending on older people was a key motivation for establishing PMC in Belo Horizonte. This section presents results from a multi-method impact evaluation on the effects of PMC on patterns of health service use by older people, including both outpatient visits to health centres (UBSs) and hospital admissions.

The effects of PMC on outpatient service use.[11]

Data on outpatient health service use come from SUS and cover visits made by people aged 60 and over to the city's 76 UBS health posts from April to June 2018. We use patient addresses to construct a proxy indicator of socio-economic status based on separate data set for 275 micro-districts produced by the public Institute for Applied Economic Research (Costa and Oliveira, 2015).

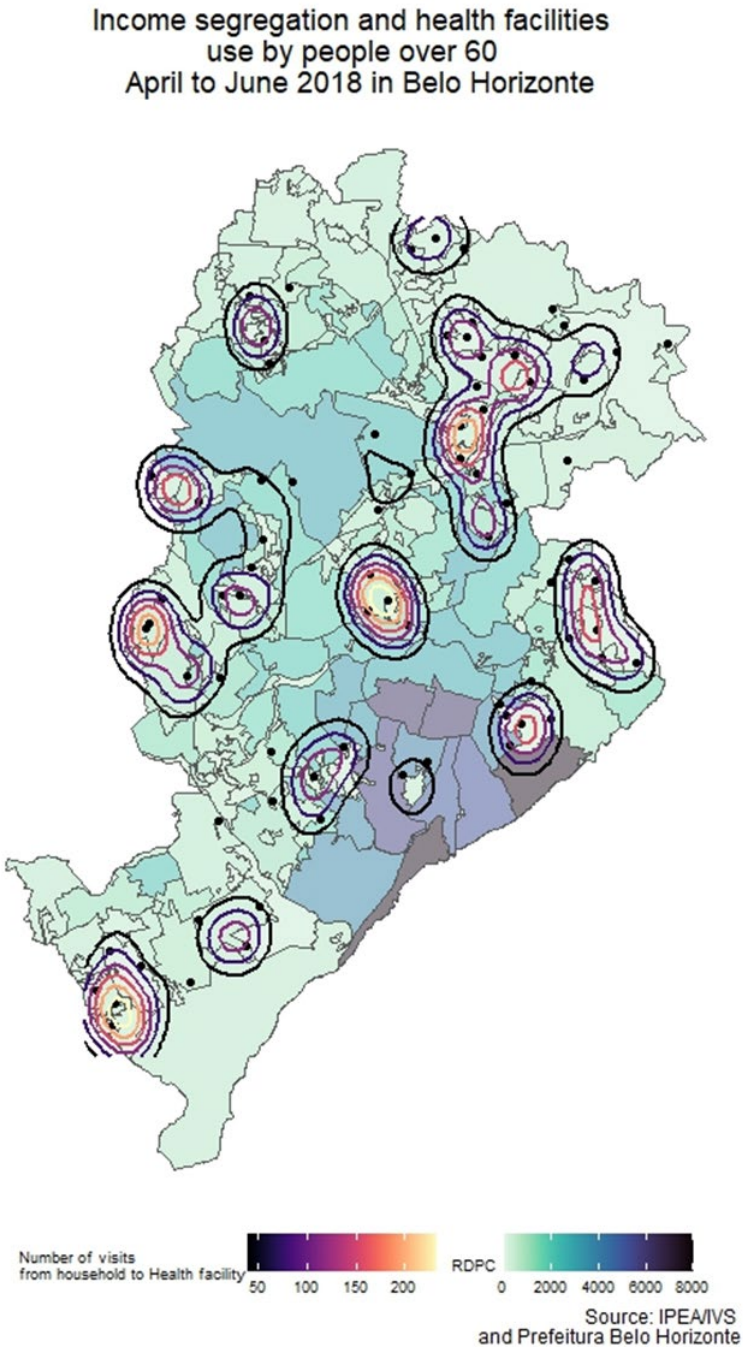
Between April 2018 and June 2018 there were 87,455 visits by people aged 60 or more, involving 24,554 different individuals (of whom 366 were in PMC). The large majority (92%) of people aged 60 or more living in Belo Horizonte made no visits to a UBS over this period.

The probability of making a visit to a UBS was strongly associated with the distance between the older person's home and the health centre. Figure 4.1 is a map of districts in Belo Horizonte municipality. The shading refers to median household per capita income for each district, with lighter green indicating lower income and the black dots the locations of UBSs. The contour lines refer to the number of visits to health posts by people aged 60 or more, based on their geo-referenced home addresses. These contour lines show that utilization is strongly clustered around health centres: on average older people who live closer make more frequent visits. Rates of utilization show a pronounced distance decay effect over short distances. This reflects Belo Horizonte's hilly terrain and steeply sloping streets, which create specific difficulties for accessing services for older people with limited mobility and who lack private transport.

The evaluation team developed and tested two theories of change relating to patterns of outpatient service use. The first is that PMC is associated with a higher frequency of outpatient visits for rehabilitation. A key objective of PMC is to facilitate older people's recovery after a hospital stay and to reduce their risk of readmission. Consequently, the case review teams place a strong emphasis on access to rehabilitation. The second theory of change is that PMC is associated with a higher frequency of planned versus unplanned outpatient visits. Family care support workers receive some basic training to recognize warning signs of potential acute health problems and are required to report them immediately to health centres.

Figure 4.1. Spatial patterns of health centre utilization and income level for people over 60, April to June 2018, Belo Horizonte.

[11] For a more detailed account of this research design, methods and findings see Lloyd-Sherlock, Giacomin and Sempé (2022).



We matched outpatient health service use data to membership of PMC and created a matched comparison group of non- PMC older people with similar characteristics. This considered individual sex, age, month of visit to the health care, household location and distance to the health centre. Socio-economic data were not available for each older individual, but it was possible to make an estimate based on linking the address of each older person to micro-district level data on the social vulnerability index (household economic dependency ratio, life expectancy in years and per capita household income). Our comparisons found a higher incidence rate for planned

visits relative to unplanned ones for PMC patients compared to the non- PMC controls, and a higher incidence of visits for rehabilitation. This effect was consistent across different matching techniques and analytical models. For example, Poisson models using Coarsened E Matching show a higher incidence rate for planned visits relative to unplanned ones (1.3; 95% confidence interval 1.1 – 1.4) for PMC patients and a higher incidence of visits for rehabilitation (3.4; 95% confidence interval 1.7 - 6.8).

Qualitative data supported both theories of change. They provide detailed accounts of how family care support workers assist older people to manage chronic health conditions which might otherwise lead to emergency health visits [Q4.1]. Helping to manage medication was especially important since many older people and family caregivers had limited literacy [Q4.2]. The interviews also show a strong emphasis on rehabilitation after hospital stays [Q4.3].

> Q4.1. *The Family Care Support Workers carer sets up his oxygen supply and stays with him chatting about this and that… She's always on the look-out in case there is anything different about him. She notices little things and then she'll tell me: "Look, there must be something going on with him. I'll have word with the people at the health centre."* (I47, F, Family Caregiver)
>
> Q4.2. *We work with many highly deprived families where nobody can read or write or administer medicine properly.* (I12, F, Psychologist, CRAS)
>
> Q4.3. *We find that older people get some strength back when they're not always stuck in bed or a wheelchair, and thanks to the physio they do with the carer. And as they get more mobile, they don't get bed sores anymore…. These are all little things, but when you put them all together, they have a big effect on older people's healthcare needs.* (I15, F, Social Worker, CRAS)

Effects of PMC on inpatient service use.

The evaluation team explored associations between PMC and average length of hospital stay and average cost of hospitalization. These outcomes were derived from a theory of change that PMC facilitates hospital discharge by increasing confidence in community support for older patients, reducing length of stay and the total cost of the hospitalizations.[12]

The analysis is based on Ministry of Health hospitalization data for April 2011 to December 2020 (DATASUS, 2020). Through a common identifier, we found 588 hospitalizations of PMC members over this period. Using propensity and inverse weight matching, we created matched comparison units. We used contextual variables (sex, age, race, treatment complexity and reason for hospitalization) to match sociodemographic and clinical characteristics of older people participating in PMC and those who were not. We used multivariate regression models to calculate the effect of being in PMC on length of stay and the total cost of the hospital stay.

[12] For a more detailed account of this quantitative design see Sempé and Lloyd-Sherlock (2022).

We find statistically significant associations between enrolment in PMC and both length of stay and total cost of the hospitalization. Across all model specifications, enrolment reduces the average duration of the hospitalization by 0.22 days (95% CI 0.08-0.35) (Table 4.1) and reduces the average cost of each hospitalization by 375 reais (current value) (95% CI 337 - 415), which was equivalent to approximately US$100 per admission (Table 4.2).

Table 4.1. Regression results for average length of hospital stay.

Parameter	Coefficient	SE	95% CI	T	p
Intercept	-0.9	0.22	[-1.34 - -0.47]	-4.05	< .001
PMC [Yes]	-0.22	0.07	[-0.35 - -0.08]	-3.06	0.002
Sex [Male]	0.41	0.05	[0.31 - 0.50]	8.4	< .001
Age	-3.89e-03	2.78E-03	[-0.01 - 0.00]	-1.4	0.162
Ethnicity [White]	0.92	0.11	[0.71 - 1.12]	8.65	< .001
Ethnicity [Mixed]	1.28	0.09	[1.11 - 1.45]	14.86	< .001
Ethnicity [Black]	2.53	0.13	[2.27 - 2.80]	6.85	< .001
Complexity of case [Medium]	2.69	0.08	[2.52 - 2.85]	32.1	< .001
Admitted to Emergency Room [Yes]	7.46	0.07	[7.32 - 7.60]	102.39	< .001

Source: Authors

The qualitative evaluation analysis sheds further light on this theory of change. It reveals that although there was no formal liaison between PMC and hospitals when an older person was admitted, family care support workers would sometimes perform this role more informally [Q4.4 and Q4.5]. Key informants including hospital staff claimed PMC increased their confidence in safely discharging older patients back into the community, potentially reducing unnecessarily long hospital stays [Q4.6]. The qualitative data indicate that the potential for PMC to facilitate hospital discharge and hence reduce unnecessarily long stays would be even greater if more formal liaison protocols were implemented.

> Q4.4. *If the older person goes into hospital and if their family is really unable to visit, then the Family Care Support Workers may go to see them there in the hospital during their usual work hours.* (I40, M, Social Worker, CRAS)

> Q4.5. *If an older person gets really ill and there isn't anyone at home, then the Family Care Support Workers will ride in the ambulance with them. They will try to stay at the hospital until someone from the family can take over. But… hospitals are usually a long way off and so it's logistically very difficult.* (I40, M, Social Worker, CRAS)

Q4.6. *And sometimes the hospital keeps calling us here, to see if we can help with this. So, that older patients can be discharged. Otherwise, they will stay in hospital for a long time, what we call a "social hospitalization".* (I41, F, Social Worker, Extended Family Health Team)

Table 4.2. Regression results for average cost of hospital stay.

Parameter	Coefficient	SE	95% CI	T	p
Intercept	5661.42	92.04	[5481.02 - 5841.83]	61.51	< .001
PMC [Yes]	-375.77	19.8	[-414.57 - -336.97]	-18.98	< .001
Sex [Male]	201.01	17.86	[166.01 - 236.01]	11.26	< .001
Age	-12.06	0.96	[-13.95 - -10.17]	-12.51	< .001
Ethnicity [White]	-46.53	38.84	[-122.66 - 29.59]	-1.2	0.231
Ethnicity [Mixed]	-16.46	-33.07	[-48.35 - 81.28]	-0.5	0.619
Ethnicity [Black]	-66.6	48.13	[-160.93 - 27.73]	-1.38	0.166
Complexity of case [Medium]	-3874.38	49.66	[-3971.71 - -3777.04]	-78.02	< .001
Admitted to the Emergency Room [Yes]	1056.41	29.17	[999.24 - 1113.58]	36.22	< .001

Source: Authors

Key take-homes from impact evaluation on health service use.

- ✓ The impact evaluation provides quantitative and qualitative evidence that PMC has significant effects on health service utilization.
- ✓ The majority of older people in Belo Horizonte do not make regular visits to UBS health posts. Spatial analysis reveals usage is highly concentrated among older people living very close to UBSs. For many other older people, physical access to these services is very limited. As such PMC offers an essential link to local health services for care-dependent older people.
- ✓ PMC is associated with a lower share of outpatient visits that were unplanned, emergency consultations. This is likely to enhance both the technical and allocative efficiency of health services. A UK official review found that growing utilization of urgent and emergency outpatient care is leading to mounting costs and increased pressure on resources (Keogh, 2013).

- ✓ PMC is associated with a higher share of outpatient visits for the purpose of rehabilitation. This is in keeping with Brazil's national health system protocol that primary health care providers should have lead responsibility for identifying and managing adult rehabilitation needs (Macinko et al., 2018). Studies in other countries demonstrate substantial cost savings from outpatient rehabilitation (Binder et al., 2004).
- ✓ PMC is associated with shorter average length of inpatient hospital stay and lower average costs per hospitalisation, due to the facilitation of patient discharge. This effect could be strengthened by more formal liaison between PMC and hospitals.

There are no published impact evaluations of schemes comparable to PMC in other low and middle-income countries. PMC shares some elements with interventions in high-income countries, including home-based primary health care and hospital at home (Langhorn, Baylan, 2017; Màs et al., 2017). Like PMC, these interventions often combine geriatric assessment with case management based on personalised care plans and periodic monitoring (Stoop et al., 2019). However, the specific form PMC takes and the context in which it operates are distinctive. PMC does not rely primarily on teams of clinical and non-clinical professionals. Family care support workers have only a limited set of competencies, but their low cost enables a high ratio of carers to older people, permitting them to spend up to 20 hours a week with individual families. This differs to schemes in high-income countries, which typically entail shorter and less frequent visits rather than extended periods of support (Sempé, Billings, Lloyd-Sherlock, 2019). At the same time, PMC operates in settings very distinct to most high-income ones. The program runs in neighbourhoods marked by poverty and vulnerability, where older people live in housing that is poorly adapted to their needs, and whose families cannot afford private caregivers (Castro, 2022). Any effects on health service utilization must be interpreted with reference the relative scarcity of health services in Brazil, where per capita health spending is less than 10% the USA's.

Bearing these differences in mind, studies of broadly comparable interventions in high-income countries report varying rates of positive effect on unplanned admissions, readmissions, and inappropriate use of medication. There is, however, no published evidence of effects on patterns of outpatient service use, including reason for consultation or rates of unplanned visits. This reflects a general neglect of this issue in the academic literature.

Section 5. Cost analysis of Programa Maior Cuidado.

This section provides operational cost data for PMC in April 2023, as well as per capita costs for each older person included in PMC. Cost estimates for different elements of PMC were derived from a pragmatic combination of top-down and bottom-up costing methods (Cunnama et al, 2016). Top- down data are available for the civil society organization which is responsible for family care support workers. Other costs (such as Department of Health and Department of Social Assistance staff time allocated to PMC) are estimated by using bottom-up data to differentiate these specific costs from other activities in which these staff are engaged.

This section does not provide a systematic monetary analysis of the observed benefits of PMC, since (as seen in previous sections) full data are not available for all potential beneficial effects. However, it is possible to compare the costs of PMC to other interventions, and to set out some limited evidence of the value PMC generates.

Capital costs.

There are no capital costs for PMC, since it does not require new buildings or substantial new equipment; PMC uses health and social assistance infrastructure that is already present. The same is not true for other interventions, such as LTC facilities or day centres. The lack of a substantial initial outlay of capital expenditure reduces the financial entry barrier for local governments to establish programmes like PMC. The absence of capital costs removes the need for discounting calculations in this cost analysis, since depreciation effects do not apply.

Costs of the civil society organization.

The civil society organization is contracted by the municipality of Belo Horizonte to recruit, train, pay (including travel costs, equipment, and full worker rights) and manage the family care support workers, as well as one full-time supervisor for every 24 family care support workers.

The total monthly transfer to the civil society organization was 590,000 reais in April 2023[13], when PMC was servicing 675 older people, equating to a cost per older person of 874 reais (US$165 at April 2023 exchange rates) a month.

Additional costs for the Department of Health and Department of Social Assistance.

In neither department are any staff exclusively dedicated to PMC: this activity is part of a much wider set of responsibilities and activities. Consequently, it is necessary to estimate the amount of staff time specifically dedicated to PMC, as an attributable share of a joint cost. These time estimates were derived from informal discussions with staff. In general, staff found it difficult to allocate a specific value to their time inputs to PMC, since these could vary over time and usually only comprised a relatively small share of their workload. A typical response from staff in health centres and community social assistance centres was that PMC often saved them time in the long run, since it prevented more serious problems. Nevertheless, it was possible to distinguish specific time inputs, such as those related to preparing for and participating in the monthly case

[13] Quotation of the US dollar in April 2023: 1 U$=5,2981 reais.

review meetings and selecting new PMC families.

Estimates derived from community social assistance centres and health post managers were that the specific time allocation in each case were roughly one person day a month. This role was usually performed by a nurse, another family health teams professional or a mid-ranking social assistant. In each case, the average staff salary was approximately 6,000 reais a month (300 a day in a 20-day month). The total number of community social assistance centres participating in PMC was 34, and so the total cost of all community social assistance centre social workers was therefore 10,200 reais (300 x 34).

The geographical territories serviced by health posts do not coincide neatly with those covered by the community social assistance centres. Consequently, some community social assistance centres work with more than one health post, representatives of whom will attend the same monthly case review meeting. As such, our cost estimates for health post staff are derived from a ratio of 1.5 health centre staff per CRAS staff, amounting to 15,300 reais (300 x 51).

A total of 675 older people were included in PMC and therefore the monthly per capita cost of this staff time was to 37.5 reais (10,200 social assistant cost, plus 15,300 nurse cost, divided by 675 beneficiaries).

Central administrative managers in the Department of Health and Department of Social Assistance estimate that the specific time allocation in each case were roughly four person days a month. This role was usually performed by mid-ranking technical staff. In each case, the average staff salary was approximately 8,000 reais a month (400 a day in a 20-day month). As such, the value of the four days a month they each allocated to PMC is 1,600 reais. Therefore, the monthly per capita cost of this staff time was 4.7 reais (800 Department of Health cost, plus 800 Department of Social Assistance cost, divided by 675 beneficiaries).

The overall estimated monthly cost of PMC per older person.

The estimate of the overall monthly cost of PMC per older person is shown on Table 5.1.

Table 5.1 - Estimate of the overall monthly per capita cost of PMC per older person in reais

Monthly per capita cost per older person	R$
Civil society organization	874
Health and Community Social Assistance Center staff	37.5
Administrative managers in DoH and DoSA	4.7
Total	**916.2 (US$173)***

*At April 2023 exchange rates (1 U$=5,2981 reais)

Value added by PMC.

The principal benefits of PMC are likely to be enhanced quality of life for older people and family carers. Although Section 3 provides qualitative evidence that these effects are substantial,

systematic quantitative data on them (such as family carer Zarit scores) are not available. Consequently, it is not possible to allocate a monetary value to these effects, despite their likely importance.

Another potential benefit of PMC is reduced need for other kinds of public or private spending to meet these older people's care needs to a similar extent. The most direct comparison is with the market rate for a paid carer with a similar level of training and experience. In Belo Horizonte in May 2023 this was around US$60 for 15 hours of care a week (a typical amount offered by PMC), equivalent to approximately 95 per cent of the basic Benefício de Prestação Continuada pension (US$66.5 a week). Arguably, the benefit derived from a private paid carer would be less than that of a PMC family care support worker, since the former are not integrated into a wider set of health and social assistance services, such as the joint working group monthly case reviews.

The cost of operating PMC can also be compared to the cost of running long-term care facilities. Although LTC facilities represent a different kind of service, their theoretical purpose is the same: to meet the needs of care-dependent older people. Without PMC it is likely that demand for LTC facilities services would be greater. In May 2023 Belo Horizonte municipality paid subsidies to 28 private LTC facilities. The monthly per capita payment was 2,300 reais. These LTC facilities are also permitted to retain 70% of the Benefício de Prestação Continuada pension of each older resident, equivalent to 924 reais. As such, the combined cost per older person per month is 3,224 reais. Due to a shortage of capacity, over 300 older people were on waiting lists for a place in a subsidised LTC facilities in 2022 (Lambert and Fuscaldi, 2022). Private LTC facilities without state subsidies tend to be more expensive: monthly costs are very variable, but usually exceed 5,000 reais.

Section 4 shows that PMC has a significant indirect effect on public spending on inpatient hospital services by reducing average length of hospital stay and average costs per admission. PMC also enhances patterns of health post service use by older people both by promoting planned, rather than emergency consultations, and by higher proportions of consultation for rehabilitation. It is not possible to estimate the monetary value of these effects, but they are likely to be significant.

Finally, PMC represents a livelihood opportunity for mainly female family care support workers who are recruited from deprived communities with limited alternatives for decent work. The average number of older people assisted by each Family Care Support Workers is 3.7. As such, the minimum wage received by these FCSWs (3,120 reais a month in May 2023) represents 92.0% of the cost of each older person included in PMC (3120/3.7 = 843.2; 843.2/916.2 =92.0%). Rather than a "sunk cost", the salaries paid to FCSWs represent a form of productive social protection for a disadvantaged group.

Section 6. Building on Programa Maior Cuidado in Brazil and the wider region.

The Federal Ministry of Health (MoH) has been co-funding the impact evaluations of PMC since 2018. One product of these evaluations is a manual of how to implement similar interventions in other Brazilian municipalities. The broadly positive results of these evaluation prompted the MoH to fund two pilot interventions in new municipalities: the cities of Salvador in Bahia State and Contagem in Minas Gerais State. These pilot interventions are being initiated in 2023 and have two key objectives:

1. To assess the feasibility of establishing interventions modelled on PMC in new settings. This will include the need to adapt the Belo Horizonte version of PMC to different contextual factors. Recognizing the challenges of intersectoral projects, the pilots will pay particular attention to the feasibility of achieving effective collaboration between municipal departments of health and social assistance.

2. To develop and extend the evidence base on PMC. Unlike Belo Horizonte version of PMC, the pilots will permit the application of a baseline survey, which will include data not systematically collected by Belo Horizonte version of PMC, such as family care burden and care capacity. The pilots will also include controls, to support robust quasi-experimental evaluation of effects.

The evaluation team and Ministry of Health are supporting and coordinating across the pilots and new schemes, treating them as an incipient national network of PMC-type evaluations. This may contribute to Brazil's first ever National Care Policy, which is currently under development.

Beyond Brazil, PMC has been show-cased as the only example of good practice for integrated long- term care in the global south (WHO, 2021). It has also been show-cased in publications by UN Women, the International Social Security Association, and the American Association of Retired People (UN Women, 2017; Lloyd-Sherlock et al, 2022; Lloyd-Sherlock et al, 2021). This interest reflects the potential scope to develop similar interventions in other countries, which are facing similar challenges.

Section 7. Key lessons and areas for further research.

This report presents an overview of a novel community-based intervention for older people living in deprived neighbourhoods in the Brazilian city of Belo Horizonte. PMC began operation in 2011 and by December 2022 3,062, families had received support or were continuing to do so.

The report describes PMC design and how it operates in practice. PMC has some important elements that distinguish it from other interventions for older people. These include the degree of cooperation between local government health and social assistance agencies, as well as the specific roles and competencies of family care support workers. The report shows that the structure and operational processes of PMC build on and link back into the existing local infrastructures of health and social assistance services, such as community social assistance reference centres (CRAS) and local health posts (UBS). Despite some shortcomings, PMC is shown to operate effectively, and it appears to be highly valued by health and social assistance staff, as well as by older people and their families. Over time some reforms have been made to PMC operational protocols and information systems to enhance monitoring and intersectoral collaboration. By 2019 PMC had been implemented across all CRAS in Belo Horizonte.

The report draws on qualitative and quantitative data to assess different potential impacts of PMC. This includes qualitative evidence that family care support workers (FCSWs), in conjunction with local health and social assistance staff, help some older people and caregivers to manage chronic health conditions and reduce risks of acute health episodes. Examples include assisting with use of medication, promoting healthy behaviours and identifying early signs of new health problems. Additionally, FCSWs were an important social resource for older people, addressing issues such a loneliness, neglect and low esteem. The report also presents qualitative evidence on the benefits PMC provides to family caregivers, with FCSWs sharing care responsibilities, providing respite from continual care work and promoting good care practice. PMC also offers vulnerable families more general forms of social support, to reduce situations of conflict and promote more cooperative caregiving.

A combination of qualitative and quantitative evidence demonstrates that PMC had important effects on patterns of health service use. Older people were less likely to visit health centres on an unplanned, emergency basis. They were more likely to do so for consultations relating to rehabilitation. Compared to similar older people admitted to hospital for the same reasons, those in PMC had shorter average stays at a lower cost. These effects show that health care and social care services for older people are very closely linked, whereby the availability of effective social care substantially influences inpatient and outpatient service use. In the case of PMC, these effects could be strengthened in some ways, such as through more direct liaison with hospitals.

The report presents a cost analysis for PMC, which estimates that the monthly cost for each older person in May 2023 was US$173. This is less than the market cost for a similar amount of support from a private caregiver: US$240. It is also less than the monthly per capita cost of state-funded long-term care facilities (US$655 at current rates). Notably, 92.0% of the cost of PMC was allocated to providing a basic wage to the Family care support workers, a high proportion of whom were women from disadvantaged neighbourhoods. A key reason for the low cost of operating PMC is that it is built on pre-existing community social assistance and primary health care infrastructure and services.

With support from the Federal Ministry of Health, schemes modelled on PMC are now being developed in two new Brazilian cities. PMC has also received international attention as an intervention that may offer useful lessons for other countries. This high level of national and international interest in PMC is partly due to the scheme's unusual elements. However, it also reflects the quantity and quality of impact evidence, which is not usually available for similar interventions. For example, São Paulo's Programa Acompanhante de Idosos (PAI) scheme shares some features with PMC, but is run exclusively by health agencies, offers families fewer hours of weekly support and deploys specialist health teams. Although descriptive information about PAI is available, there are no published evaluations of PAI's effects on older people and their caregivers or on service use. Similarly, detailed descriptive accounts and process evaluations are available for the operation of Chile's Chile Cuida scheme and Uruguay's National Integrated Care System, but these do not include evidence of impacts or effects (Rosales, Monreal and Villalobos, 2020; AARP, 2020). In China a range of related interventions have been piloted at local government level, but they have not been evaluated (Hu and Glavin, 2023). Exceptionally, a similar community-based intervention in Thailand has been robustly evaluated and finds significant effects on caregiver burden, as well as on limiting functional decline and depression among older people (Aung et al, 2022). However, this Thai evaluation does not include potential effects on health service utilization. Collecting impact evidence about complex interventions is challenging, but it is necessary to generate policymaker interest.

A key issue is whether interventions like PMC should be operated jointly by different government departments, or just by one (either health or social assistance). Although there are potential benefits from collaboration between government departments, achieving it in practice is often challenging. PMC was initially affected by issues with shared information systems, inter-departmental communication and clear delineations of roles and competencies. These issues were addressed by reforms implemented after 2019, including a formal inter-departmental agreement. Consequently, PMC's experience shows that intersectoral collaboration can be made to work. Combining the skills and resources of local health and social assistance professionals enabled PMC to address a wider set of issues than just older people's functional and clinical status. The qualitative data presented in this report demonstrate the added value of addressing other forms of vulnerability affecting older people, as well as their caregivers and families.

The available evidence about PMC provides useful insights for policymakers in Latin America and the Caribbean, but this evidence remains incomplete. There is a need to build on the available knowledge base in several ways. First, current evidence is limited to the operation and effects of PMC in Belo Horizonte. There is a need to extend this knowledge to other locations, to assess both the degree to which PMC is replicable and whether it has similar impacts in different local environments. This should also consider local political conditions that either enable or hinder this form of intersectoral collaboration. The ongoing pilot projects in Minas Gerais and Bahia will address these knowledge gaps. Second, there is a need for more quantitative data on how PMC affects the wellbeing of older people and their caregivers, as well as patterns of health service use. This will require more complex and rigorous studies such as randomized control trials.

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Appendix

Appendix I. – Evaluation questionnaire for inclusion in Programa Maior Cuidado

PMC applies a systematic questionnaire to assess the eligibility and priority of older people for inclusion in the scheme. This survey was jointly developed and is jointly applied by staff from the Department of Health and Department of Social Assistance. It generates a point score, with 60 points the minimum value for eligibility.

CRITERIA				
Person aged 60 years or more who is semi-dependent or dependent				
Residing in an area corresponding to a CRAS				
To be registered at Health corresponding to a CRAS				
Monthly family income below 3 minimum wages or per capita income below half the minimum wage				
Point score more or equal to 60 points				
1. USER IDENTIFICATION				
Name of User:				
Age:		Telephone:		
Address: Street/Av:				
No.:	Complement:	Neighbourhood:		
Reference Familiar:				
CRAS Reference of User:				
Nº. medical record CRAS:		Nº of SIGPS		
Nº of NIS		Nº. of Card SUS:		
Registered Health Centre		Medical Record Nº.:		
2. FAMILY COMPOSITION AND INCOME				
Name	**Date of birth**	**Relationship to older person**	**Income**	**Source of income**
Total family income				
Income per capita				

3. AGE FACTORS	
Age	**Points**
75-79	**2**
80+	**4**
Total points	
4. VULNERABILITIES AND SOCIAL RISKS	
4.1 Vulnerabilities in Income	**Points**
Families with income per capita under 1/2 minimum wage	**3**
Families with income per capita under 1/4 minimum age	**5**
Total points	
4.2 Families with priority status for government support	**Points**
Beneficiaries of social assistance grant, including Programa Bolsa Familia	**10**
Registered with Social Protection Services.	
Total points	
***4.3 Relational vulnerabilities affecting family caregiving capacity*.**	**Points**
Family - With a child, a teenager, a person with a disability, or more than one older person; - With children or teenagers out of school; - With an adolescent under a judicial socio-educational measure; -With a prisoner or former member of the prison system; - With a person who abuses alcohol or other drugs; - With a mentally ill person; - With conflict situations that affect daily caregiving; - With a member who experiences prejudice or discrimination (age, ethnic-racial, gender, religiosity, social and economic conditions (sexual orientation, or disability, among others); - With a member who experiences a situation of isolation, confinement or separation;	**11**
Older Person - Grade 3 care dependency and/or with mobility limitations, due to the existence of barriers at home, making accessibility difficult; - remains alone for long periods; - exposed to risks of social isolation, confinement, separation, exclusion or abandonment; - returning to the family environment after institutionalisation; -low participation in family and community activities;	**11**

Family caregiver **-** in situation of emotional or physical stress caused by care for the older person; - has interrupted work activities or is unable to exercise them, due to caregiving; - is an older person; - performs the role of caregiver alone; - abusive use of alcohol or other drugs or with mental suffering or disability; - in prolonged treatment for health problems;	**11**
Total points	

5. FUNCTIONAL CLINICAL EVALUATION			
Indicator	**Description**	**Points**	
Self-perception of health	In general, compared to other people your age, is your health: • average or bad • Great, very good or good. If the older person cannot answer, the caregiver or a family member or a proxy can answer for them.	( ) average or bad (1 point)	( ) Great, very good or good (0 point)
Clinical factors	Multimorbidities (> 5 chronic diseases) or Polypharmacy (regular use of > 5 medications/day)	( ) Yes (1 point)	( ) No (0 point)
	Has domestic oxygen therapy	( ) Yes (1 point)	( ) No (0 point)
	Presence of skin lesions	( ) Yes (1 point)	( ) No (0 point)
	Recent hospitalization (within the last 6 months) or recurrent hospitalizations (within the last 2 years)	( ) Yes (1 point)	( ) No (0 point)
Cognition	Forgetfulness that makes it difficult or prevents carrying out daily activities (cognitive impairment)	( ) Yes (1 point)	( ) No (0 point)
	Behavioural disorders (hypersexuality, apathy, aggressiveness, wandering, restlessness)	( ) Yes (2 points)	( ) No (0 point)
Mental health	Despondency, sadness, or hopelessness (assess depressed mood)	( ) Yes (1 point)	( ) No (0 point)
	Sleep disorders (insomnia, daytime naps, etc.)	( ) Yes (1 point)	( ) No (0 point)
	Diagnosis of mental disorder (schizophrenia, severe neurosis, psychosis, etc.)	( ) Yes (2 points)	( ) No (0 point)

Mobility	- Unintentional weight loss (weight loss that did not occur by your own decision) of at least 4.5 kg or 5% in the last year and/or - Calf circumference < 31 cm and/or - Body mass index < 22 kg/m² OR - Morbid obesity BMI > 40 Kg/m².	( ) Yes (2 points)	( ) No (0 point)
	- Inability to hold small objects or touch the back of neck with both hands and/or difficulty getting up and sitting in a chair or walking and/or 2 or more falls within the last year.	( ) Yes (1 point)	( ) No (0 point)
	Involuntary loss of urine or faeces	( ) Yes (1 point)	( ) No (0 point)
Total points			

5.2 Autonomy of the Older Person

Autonomy is the individual ability to decide and command one's actions, establishing and following their own rules. It means decision-making capacity and depends directly on cognition and mood.		
Considering the cognition and mental health indicators, does the team assess that the older person is able of deciding **and** commanding their own lives?	( ) Yes (0 point)	( ) No (1 point)
Total points		

5.3 Environmental Assessment of the Older Person

Indicator	**Description**	**Points**	
Family support	Older person receives all the necessary care, although, the caregiver experiences overburden or difficulties.	( ) Yes (1 point)	( ) No (0 point)
	The older person receives some of the necessary care.	( ) Yes (3 points)	( ) No (0 point)
	The older person does not have a caregiver (even with family members at home).	( ) Yes (4 points)	( ) No (0 point)
Social support	The older person has social support from people in the community who offer daily care.	( ) Yes (0 point)	( ) No (2 points)
Environmental Assessment	Residence conditions: locomotion areas; lighting; bathroom; steps. An older person's residence has an architectural barrier and/or presents a higher risk of falls and/or precarious conditions.	( ) Yes (2 points)	( ) No (0 point)
Total points			

Check one option on each line for the functional factors.

Functional Factors	Independent (0 points)	Semi-dependent (1 point)	Dependent (2 points)	Punctuation
Cooking and Housekeeping	( ) No need of help	( ) Need partial help	( ) Needs help	
Shopping and managing money	( ) No need of help	( ) Need partial help	( ) Needs help	
Using the phone	( ) No need of help	( ) Need partial help	( ) Needs help	
Taking the medications	( ) No need of help	( ) Need partial help	( ) Needs help	
Total points				

5.5 Self-care and basic activities of daily living (*tasks necessary for the care of your body or self-preservation; self-care – to meet a basic human need).*

Check one option on each line for the functional factors.

Factors functional	Independent (0 points)	Semi-dependent (1 point)	Dependent (2 points)	Punctuation
Bathing	( ) No need for help. Can take a bath alone.	( ) Needs in help in bath to wash only one part of body, such as back or leg.	( ) Requires help for washing more than one part of body or does not shower alone.	
Dressing	( ) Handles own dressing completely without assistance.	( ) Handles own dressing completely without assistance, except for tying shoelaces.	( ) Requires help for dressing, not able to dress alone.	
Toileting	( ) Goes to the bathroom, undress, clean up, tidies clothes without help (can use bedpan or similar only at night, can use cane or walker).	( ) Needs help to go to the bathroom or for cleaning up, or for gets to dress after using bathroom; or to use bedpans/similar at night.	( ) Cannot go to bathroom alone.	
Transfer	( ) Lies down and gets up from bed or chair without help (can use a cane or walker).	( ) Lies down and gets up from bed or from chair with help.	( ) Restricted to the bed.	
Continence	( ) Entirely controls urination and evacuation.	( ) Has occasional “accidents” (urinary losses or occasional feces).	( ) Use of diaper or catheter; total incontinence.	

Eating	( ) eats without help.	( ) feeds without help (take the food of dish until the mouth), except for cut meat or to spend butter at the bread.	( ) Requires help for to take The food from plate to mouth; or use in feeding tube . –	
Total points				

Grand total of functional clinical assessment:

Points:

INFORMATION ON IDENTITY OF SCREENER PREENCHIMENTO	
CRAS:	
Social assistant:	Date:
Social Protection Service Team:	
Signature:	
Health Centre:	
Health Professional:	
Health Team:	Date:
Signature:	

Appendix II. Waiting list form for Programa Maior Cuidado

Once older people have been evaluated for eligibility and priority for inclusion in PMC (see Appendix 1), their case will be assessed in the next monthly case review. Not all eligible families are immediately included in PMC as the number of family care support workers is limited. Details of families who are not immediately included in PMC are entered into this form and will be reviewed when a place becomes available.

User name	Health Centre	CRAS	Electronic medical record number	Date of visit by the Health Team	Health assessment score	Date of visit carried out by the Social Assistance team

Social Assistance evaluation score	Date of discussion in the monthly review	Total score	Referrals	Analysis status	Observation

Appendix III - Quarterly Monitoring Spreadsheet for Programa Maior Cuidado

Family care support workers complete monitoring reports which are then discussed in the monthly case reviews.

IDENTIFICATION DATA							
Name	CRAS	Team	PE - Electronic medical record number	Date of birth	Age	Score according to insertion evaluation	Gender

ACCESS TO SERVICES AND LEISURE								
Access to services and leisure								**Date of insertion in NASF***
Health Centre	CRAS	Support Groups	Church	Volunteer work	Club	Tour	Not applicable	

**NASF- Extended Family Health Team

FUNCTIONAL CLINICAL EVALUATION OF THE OLDER PERSON												
Falls			**Hospitalization**			**Oxygenation *(mark with X)***						
Last 12 months	Number of falls	Date of last fall	Last 12 months	Nº. of hospitalization	Date of last hospitalization	Oxygen therapy	Tracheostomy	Micro nebulization	BIPAP*	CPAP**	Not applicable	Other (specify)

*BIPAP - Bilevel Positive Airway Pressure; **CPAP - Continuous Positive Airway Pressure

FUNCTIONAL CLINICAL EVALUATION OF THE OLDER PERSON										
Eliminations							**Food:**	**Hydration/ Dehydration**	**Oral Health:**	**Mobility:**
Urine	**Feces *(mark with X)***									
Diaper; Delay probe and diaper; Relief probe and diaper; Delay probe; Relief probe; Habitual;	Habitual	2 days without a bowel movement	Hemorrhoid	Colostomy bag	Diaper	Not applicable	AT; Others; Gastros-tomy; Probe; Choke; Habitual		Mouth injury; Mobile prosthesis Fixed prothesis; It has teeth;	AT; Others; Restricted to bed; Wheelchair; Crutch; Walking stick; Walker; Alone;

FUNCTIONAL CLINICAL EVALUATION OF THE OLDER PERSON																	
Body and skin care *(mark with X)*						**Skin lesions (local)**											**Simple dressings**
Dry skin	Itch	Thin skin	Oedema	Not applicable	Other (specify)	Occipital	Shoulder	Shoulder	Elbow	Trochanter	Iliac crest	Sacral	Knee	Malleolar	Calcaneus	Hallux	

FUNCTIONAL CLINICAL EVALUATION OF THE OLDER PERSON													
Sleep *(mark with X)*					**Mental health *(mark with X)***								
Daytime sleepiness	Insomnia	Snores	Not applicable	Other (specify)	Depression	Anxiety	Disinhibition	Disorientation	Memory change	Aggressiveness	Apathy	Not applicable	Other (specify)

FUNCTIONAL CLINICAL EVALUATION OF THE OLDER PERSON												
Other health conditions that require attention *(mark with X)*												
Hypertension	Diabetes Mellitus	Osteoporosis	Osteoarthritis	COPD*	Neoplasm	Stroke sequelae	Epilepsy	Parkinson's	Dementia or Alzheimer's	Urinary incontinence	Not applicable	Other (specify)

COPD - Chronic Obstructive Pulmonary Disease

FUNCTIONAL CLINICAL EVALUATION OF THE OLDER PERSON												
Life habits *(mark with X)*				**Medicines**		**Usual Prescription *(mark with X)***						
Smoking	Alcoholism	Not applicable	Other (specify)	Polypharmacy (more than 05 drugs)	**How to use it:** AT; Others; Self medication; With help; Alone;	Topic	Injectable	inhalation	Oral	Rectal	Not applicable	Other (specify)

FUNCTIONAL CLINICAL EVALUATION OF THE OLDER PERSON														
Warning signs (mark with X) Obs.: Field to be filled in by the team together with the PMC caregiver														
Colour changed	Mental confusion	Agitation	Prostration	Shortness of breath	Severe pain	Acute pain	lack of appetite	Hypothermia	Fever	Vomit	Diarrhoea	Bleeding	Not applicable	Other (specify)

IMMUNIZATION							HEALTH MONITORING		
Vaccination (mark with X)							Care Plan		
Influenza	Covid-19	Adult duo	Pneumo 23	Yellow fever			Do you have a Care Plan?	Last update date	**Justification:** Inactive - Other; Inactive - Death; Inactive - Institutionalization; Inactive - Family Reintegration; Active – PMC* Reinsertion; Active

Appendix IV. Social assistance and health care plans for older people included in Programa Maior Cuidado

Family care support workers (FCSWs) are expected to work with family members of older people to develop and agree a personal care plan for the older person. The design of this care plan includes two sections. The social assistance care plan relates to a broad set of social issues affecting older people, their caregivers and families. The health care plan relates more specifically to clinical duties. The Department of Health and the Department of Social Assistance liaised during the development of these two plans, to enhance their intersectoral complementarity.

A. Social Assistance Care Plan.

Axle	Goals	Actions
Function protective from the Family	**Support the family in caring for the older person, in improving their quality of life.**	[ ] Perform elder care according to the guidelines of the CRAS and Health Centre.
		[ ] Support carrying out activities involving the older person and their families, including organization of accessible spaces in the house, environmental hygiene, creating schedules and reminders for medication intake
		[ ] Support the older person in self-care activities, such as bathing, dressing, performing personal hygiene, eating, sunbathing, moving around the territory, among others.
		[ ] Reinforce the guidelines of the CRAS and the Health Center on maintaining a welcoming and humanized environment where the elderly remain, as well as the NASF guidelines on accessibility and safety.
		[ ] Valuing the care actions of the family caregiver.
		[ ] Encourage the family to participate in meetings and actions developed at CRAS and at the Health Center.
		[ ] Encourage the family caregiver to participate in local leisure, sports and cultural activities.
		[ ] Support family caregivers' opportunities for moments of rest, self-care and access to rights.
		[ ] Instruct the family about imminent dangers at home that may make it difficult for the older person to move around, such as untied shoelaces, slippers, rugs, animals, among others. Sharp objects that cause risk to the older person.
		[ ] Support the family so that the older person attends consultations and medical examinations, reminding them of the scheduled dates, the necessary documents and important situations to be reported regarding the older person.

Axle	Goals	Actions
Function protective from the Family	**Support the family in caring for the older person, in improving their quality of life.**	[ ] Encourage the family to take into account the dietary preferences of the older person, respecting health restrictions and guidelines. When necessary and as directed by the CRAS, the caregiver must prepare the older person's food.
		[ ] Encourage family participation in cognitive stimulation activities, with moments of listening and conversation with the older person.
		[ ] Support and accompany the older person in external activities such as a walk or a social event.
		[ ] Create a diary with the family, containing the care provided, remarkable moments and the life story of the older person.
Family ties and Community	**Contribute to the participation of the older person in family and community living spaces**	[ ] Organize the environment where the older person stays, keeping it clean and airy. Encourage the family to keep personal objects of the older person that are part of their life story in that environment.
		[ ] Encourage the participation of users and their families with the Coexistence and Strengthening of Bonds Service, within opening hours, staying with the older person during the day.
		[ ] Encourage the older person and his/her family to visit relatives and friends residing in the community .
		[ ] Encourage visits and accompanying the older person to community spaces.
		[ ] Stimulate the family to value significant dates for the older person
		[ ] Be aware of social and daily activities already carried out by the family, which may involve the older person, encourage the family to involve them.
		[ ] Promote and encourage family members and friends to engage with the older person. It is to guide them to provide the necessary care for the older person.
Development from the autonomy of older person	**Contribute to the older person having experiences that favor the achievement of autonomy, independence and well-being.**	[ ] Encourage the older person to carry out activities that they can do alone.
		[ ] Establish a routine for planning activities with the older person.
		[ ] Recover habits and skills of the older person and encourage them to carry out artistic, cultural and religious activities, according to their interest, such as: painting, playing a musical instrument, craft activities, writing, reading, listening to music, taking care of plants.

Axle	Goals	Actions
Development from the autonomy of older person	**Contribute to the older person having experiences that favor the achievement of autonomy, independence and well-being.**	[ ] Encourage the older person to take care of themselves, maintaining their self-esteem
		[ ] Encourage the older person to participate in recreational activities and cognitive and intellectual stimulation.
		[ ] To encourage the older person to accomplish choices and to take decisions.
		[ ] Supervise the instrumental activities of life practice carried out by the older person, avoiding injuries.
		[ ] Encourage the family to accompany the older person in activities, allowing them to perform in these.
		[ ] Sensitize the family about the importance of preserving the autonomy of the older person.
		[ ] Establish a routine in space-time context with the elderly, promoting walking activities with them in the territory so that they recognize the community, rescue their life history through photographic records, cards and other materials that favor their location in time and space.
		[ ] Develop activities that preserve and encourage autonomy, social participation of the older person, favouring the strengthening of mutual protection among family members.
		[ ] Promote constant dialogue with the older person, involving the family and the community.
		[ ] Rescue and value the life story of the older person, their family and community.
Guarantee of Rights	**Contribute to access to services, programs, projects, social assistance benefits, income transfer and as other public sector policies.**	[ ] Inform the CRAS about needs of the older person and their family.
		[ ] Contribute with guidance to the family on existing public services and the offers of the social assistance network in the territory.
		[ ] Support the family in guaranteeing access of the older person to public services.
		[ ] Sensitize the family about the importance of supporting the older person in accessing their rights, family and community life.

B. Health Care Plan. (Example)

TASKS	PERSON RESPONSIBLE FOR CARE				
	PMC CAREGIVER	RELATIVES	HEALTH TEAM		
			ESF	NASF	OTHERS
( ) Accompany the older person in consultations at the health centre	X	X			
( ) Accompany home visits of health professionals	X	X			
( ) Encourage and accompany the older person whenever possible in extra-domiciliary activities; articulate with those responsible for the activities about the needs for the participation and socialization of the elderly	X	X			
( ) Schedule a consultation and/or visit to the older person and their family.			X	X	X
( ) Monthly visit by the Community Health Agent.			X		
( ) Stimulate the practice of regular and pleasurable physical activities.				X	
( ) Stimulate social interaction, participation in commemorative dates.				X	
( ) Encourage the use of the older person card as an identification document in any social setting.	X	X	X	X	X

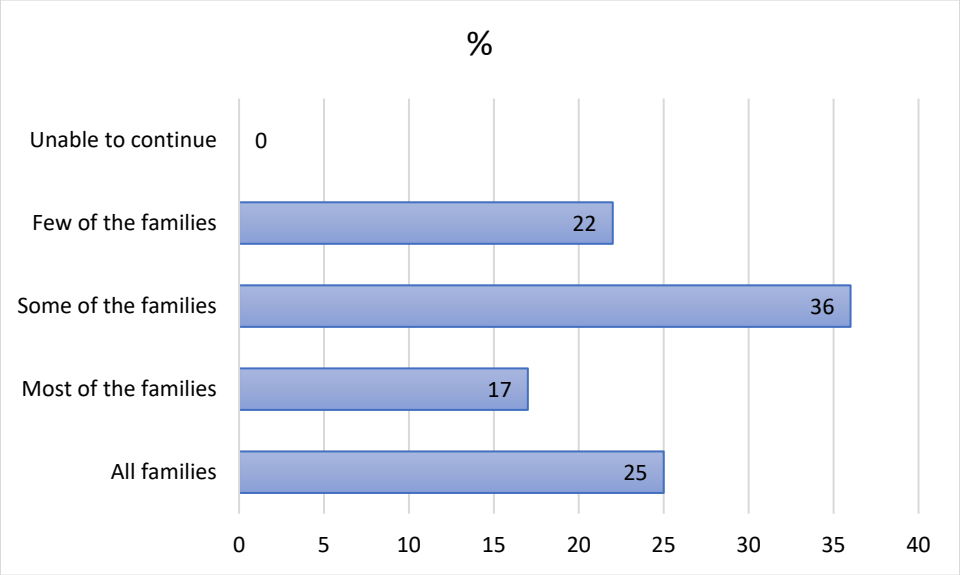
Annex

Annex I - Covid-19 stress test of Programa Maior Cuidado

The first cases of COVID-19 in Belo Horizonte were reported on 8 March 2020, shortly after completion of the initial operational evaluation. Like other cities in Brazil, rates of infection were very high in more deprived neighbourhoods and older people were at particular risk of COVID-19 mortality. It was therefore anticipated that the pandemic would substantively affect the operation of Programa Maior Cuidado and that rapid adaptation would be necessary. Consequently, the research team developed a questionnaire survey distributed by email to managers responsible for all 36 Social Assistance Reference Centres/ Community Health Centres where Programa Maior Cuidado was operating (see below).

Due to risks of infection, most home visits were initially suspended and rapidly replaced by regular telephone calls and other forms of remote communication with families. Despite the enormous pressures on local health teams, it was possible to continue the monthly joint work group, albeit on a remote basis (Figure A.1).

Figure A.1: Impact of COVID-19 pandemic on operation of families who participate to Programa Maior Cuidado.



Source: Authors

All the CRAS included in the survey reported that they were able to continue providing some level of service to Programa Maior Cuidado families. In 42 per cent of Social Assistance Reference Centres, it was possible to continue supporting the majority of Programa Maior Cuidado families during Wave 1 of the pandemic. Regular telephone calls enabled Family care support workers to continue monitoring the status of older people and maintain contact with their family carers. Family care support workers reported that some older people became more accustomed to telephone support over time, facilitating conversational interaction. Nevertheless, some family visits were

continued (QA.1), not all families had telephones and it was evident that telephone interaction was not an effective substitute for the form of support usually provided by Programa Maior Cuidado (QA.2).

> Q2.1. *For more the most vulnerable families it was still necessary to go in person -it's just not the same as a phone call.* (I15, F, Social Worker, Social Assistance Reference Centres)

> QA. 2. *The programme stopped visiting us during the pandemic, and it was very tough for us. We weren't able to take our medicine properly, because I can't read, and my wife can't see. So, I didn't take them right and then I got really ill.* (I33, M, older person)

Because Family care support workers were not officially categorized as "health professionals", they did not receive the same priority access to Personal Protective Equipment (PPE) and, later, vaccinations as other frontline health workers. This is an example of the need for stronger intersectoral recognition of Family care support workers' role. Nevertheless, by October 2020 it was possible to resume home visits, and Programa Maior Cuidado's operations rapidly reverted to their pre-pandemic model.

Questionnaire for Covid-19 stress test of Programa Maior Cuidado

a. What is the name and location of the service/sector you are in? Ex.: Health Centre/CRAS – Specialized Social Assistance Reference Centres; / Regional Health Administration / Basic Social Protection Regional: _____
b. What is your name and title? _____

Over the 12 months leading up to the COVID-19 pandemic, March 2019 to March 2020:

c. How many families did your service support through Programa Maior Cuidado?_____
d. How many caregivers were involved in Programa Maior Cuidado?_____

Please mark your reaction to the statements below:

e. PMC was effective in meeting the needs of older people and their families.

( ) I totally agree ( ) I agree ( ) I neither agree nor disagree ( ) I disagree ( ) I totally disagree

f. Programa Maior Cuidado was efficient in reducing the stress and care demand of the older person's relatives in the participating families.

( ) I totally agree ( ) I agree ( ) I neither agree nor disagree ( ) I disagree ( ) I totally disagree

g. List up to 3 specific challenges to operating Programa Maior Cuidado in your area before the pandemic. _____
h. Since the start of the COVID-19 pandemic in March 2020, please select a description from the following statements:

( ) It was possible to continue offering at least some Programa Maior Cuidado services to ALL families.

( ) It was possible to continue offering at least some Programa Maior Cuidado services to MOST families.

( ) It was possible to continue offering at least some Programa Maior Cuidado services to SOME of the families.

( ) It was possible to continue offering at least some Programa Maior Cuidado services to FEW families.

( ) It was NOT possible to continue offering Programa Maior Cuidado services to families.

Please select a description from the following statements:

( ) It was possible to maintain the FULL service for these families.

( ) It was possible to maintain the PARTIAL service for these families.

i. Identify up to 3 specific challenges to the functioning of Programa Maior Cuidado during the pandemic, indicating how you dealt with them:

_____