



Mary

Safeguarding adult review

December 2021

Introduction

This Safeguarding Adult Review (SAR) has been carried out by partners who are members of the Safeguarding Adult Review Panel. Governance, scope and purpose of this SAR and methodology are explained. This is followed by a summary of Mary's experience, what has been learned about partnership working, and what should be done about the learning. The report is anonymised to protect the family's privacy, so Mary is not her real name.

Governance

This report has been produced by the Safeguarding Adult Review Panel (SARP), a sub-group of Slough Strategic Safeguarding Leaders group (SLG). The SARP is authorised by the SLG to consider cases for review and to deliver reports on lessons learned. Independent scrutiny and challenge is provided by the Safeguarding Partnership independent scrutineer who has overseen the process throughout. Drafts were prepared by the chair of the SARP and scrutinised by the vice chairs and independent scrutineer as well as by the partners on the SARP. Terms of reference, including methodology were agreed by partner members on the SARP. SARP members have signed off this final draft for submission to the SLG.

Purpose of this report *(full terms or reference below)*

A SAR must be arranged when an adult in the area dies as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked more effectively to protect the adult. *(Care act 2014 Par....)* The care act guidance refers to this below:

"SABs must arrange a SAR when an adult in its area dies as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked more effectively to protect the adult. SABs must also arrange a SAR if the same circumstances apply where an adult is still alive but has experienced serious neglect or abuse. SABs are free to arrange for a SAR in other situations where it feels that there will be value in doing so. This may be where a case can provide useful insights into the way organisations are working together to prevent and reduce abuse and neglect of adults, and can include exploring examples of good practice. The adult who is the subject of the SAR need not have been in receipt of care and support services for the SAB to arrange a review in relation to them. The process for undertaking SARs should be determined locally according to the specific circumstances of individual circumstances. We do not believe a one-size-fits-all approach is an appropriate response. The focus must be on what needs to happen to achieve understanding, remedial action and, very often, answers for families and friends of people who have died or been seriously abused or neglected." (Care Act Guidance: 2014)"

In Slough, the Safeguarding Adult Board function referred to above is delivered by Slough Safeguarding Leaders' group and sub-groups.

Members of SARP carried out a scoping exercise, gathering available information and were unanimous in agreeing that this case meets the criteria for Safeguarding Adult Review. Partners agreed that there is potential for learning about whether more could have been done to support Mary in her final days.

Terms of reference

Scope: The focus is on learning about whether more could have been done to help Mary in her final days and whether such situations can be prevented in future by improvements in partnership working. The decision to review does not suggest or infer that any care giver was neglectful or abusive.

Timeframe

The review timeframe was from 15th February 2019 until the date of her death on 14th November 2019.

Aim

The SARP aim is to establish learning about partnership working with a focus on learning that has demonstrable impact.

Objectives

The following Key Lines of Enquiry (KLOE) are addressed by this SAR and were agreed by the SARP:

- What were the factors affecting the quality of Mary's life?
- Were the views of Mary established and clearly understood?
- Was her mental capacity robustly assessed, clearly documented, and regularly reviewed?
- Did those close to her get support and did they see themselves as carers who could get help?
- Did professionals identify family members as carers? If not, why not?
- Were there missed opportunities to instigate partnership working that might have helped Mary?
- Were there examples of good practice?
- What needs to change?

METHODOLOGY

The review was carried out in 5 phases.

PHASE ONE: Scoping

The scoping exercise involved each partner agency providing a summary of their involvement and their initial views on what can be learned. These reports formed the basis for analysis and provided a focus for the Key Lines of Enquiry.

PHASE TWO: Multi-agency analysis

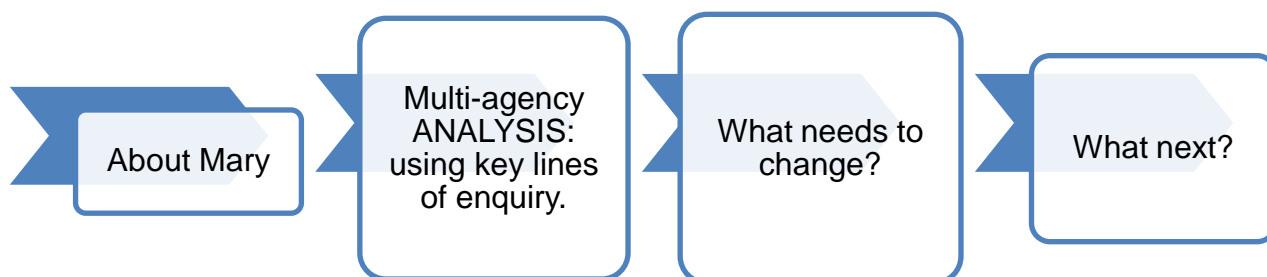
A multi-agency analysis event was held and involved those agencies who provided reports and practitioners and managers who either provided services to this family or families in similar situations. The event analysed the information provided and established a multi-agency view on key lines of enquiry.

PHASE three; DRAFTING

The SARP chair drafted the report with the two vice chairs, (one from TVP and one from the Local Authority) and the CCG. This was then shared with the wider SARP members for consultation and comment. The report was signed off by the SARP group on November 9th and by the SLG on 17th December.

Report structure

The report is structured as follows:



Constraints

The SAR was constrained by the lack of direct input by family members. The SARP group chair wrote to Mary's husband, but no reply was received. The decision not to pursue this was made with the chair and vice chair together as it was not possible to establish whether approaching him further and repeatedly would cause distress and/or family tensions.

About Mary:

Mary was a 77-year-old white Irish woman who lived with her husband in their own home in Slough. The couple had 2 adult children: a son and a daughter. The daughter did not live at the premises. Her son made regular and frequent visits to the home.

Mary was admitted to hospital via ambulance on 13th November 2019. Her son had made the call to the ambulance service as he was concerned that she had not eaten or drunk any fluids in the preceding 5 days and had reduced mobility and weight loss. The ambulance service reported her condition as "unkempt" and that she was wearing "soiled" clothing. The hospital had made similar observations and confirmed that she had had sepsis. Mary died at 02.45 on 14th November. The cause of death, established from Post-mortem was "Metastatic

Carcinoma of Unknown Primary". This is cancer which spread throughout the body, and it was not possible to establish from post-mortem where it had started.

Mary had a history of rheumatoid arthritis and Chronic Obstructive Pulmonary Disease (COPD). She was a heavy smoker. She failed to attend several appointments at the hospital in the year preceding her death and it is not clear why she did not attend. At one appointment with her GP in September 2019 she talked about her memory loss. A screening test confirmed this, but she declined the offer of a referral to a memory clinic. There is no suggestion in reports provided to this review that her non-attendance for clinical appointments was due to neglect. Mary frequently displayed a resistance or refusal to attend appointments and so only engaged intermittently.

On 11th November, two days prior to her admission, her son called the GP who made a home visit. Her son informed the GP that she had had shortness of breath and a cough for the preceding 2 days and had been sleeping on the sofa. He was also concerned that his mother appeared to have lost a lot of weight in the preceding 5 days. The GP also noted that blood tests requested the previous September had not been done as she was reluctant to go to doctors. She had inhalers but was not using them. Mary did not want to see a doctor and needed much persuasion to allow the GP to examine her on that day. The GP prescribed antibiotics and urged her to get blood tests done and to have a chest x-ray and to attend her rheumatology appointment. Her son agreed to take his mum for these tests. The GP also advised her and her son about the signs of sepsis and followed up later to find out if she had indeed gone for the blood tests and chest x-ray. By then, Mary had died.

Analysis (Using the key lines of enquiry)

What were the factors affecting the quality of Mary's life?

Mary's physical health was challenging as she suffered from rheumatoid arthritis and COPD and smoked quite heavily. These factors affected her health quite seriously as her mobility reduced. Towards the end of her life, she confined herself to the sofa and so her state of hygiene deteriorated, indicating that her ability to attend to basic personal hygiene was being compromised. The multi-agency analysis workshop spent some considerable time exploring the different perspectives of neglect and self-neglect among those in the group. It is clear in the accounts provided by those who directly cared for her in those hours before her death that she was in a neglected state. It is not possible to determine how long it took for Mary to be in this condition, but it was agreed that it is likely to have been several days at least. Exploring neglect and self-neglect generated discussion and challenge about the unconscious assumptions made by the phrase "neglect". Clarification was needed on whether the phrase implied that a person neglected her whether by omission or commission and it was difficult for the group to focus only on Mary's presentation to clinicians on that night. This suggests more work needs to be done by the partners to create a common multi-agency understanding of neglect and self-neglect and this is already in the safeguarding partnership strategic plan.

Due to the lack of engagement from the family the review is unable to be clear about what life was like for Mary in those last weeks and days. It can be surmised that as a female in a household with men, the husband living there and the son visiting, she may have been reluctant to accept any offer of help with her personal hygiene from either of them. The review is not informed about whether they offered to help or whether they just did not recognise her rapidly deteriorating condition. Mary also had a daughter who, it is believed,

has her own family life outside of Slough. She was with her mother in her last hours, but the review was unable to establish the nature of their relationship. It would appear from the reports provided that her son was a constant figure in her life and regularly visited the family home and worked hard to get the right support for his mother. Examples of this can be seen in him calling the GP on the 11th November and the ambulance on the evening of 13th November, as well as bringing her to the appointments she agreed to attend in the preceding years.

Her son has his own needs as the substance misuse service provider highlighted. The review learned that he was also receiving services from adult mental health providers*. He had been compliant with his substance misuse treatment and often mentioned his commitments to his mother when making appointments. He also had a track record of criminality which was extensive and serious as indicated by the many entries made in police reports. There is one example of police attending the home to search for stolen property so suggesting that Mary knew about his problems.

It is reasonable to deduce that Mary may have been worried about her son and his future and it is likely that this may have affected the quality of her life in preceding months or years. This being so, she is very unlikely to share her worries about that with any professional.

What have we learned?

These factors affected the quality of Mary's life and may well have played a part in her reluctance to engage professionals who were there to help her. Research*(ref) and national experience indicate that families will fiercely guard their personal issues from professionals. The issues affecting their lives can sometimes be normalised as part of that family's culture and so may not even be seen by them as problematic. This explains why even when professionals do make further enquiries, the person remains reluctant to get help. Mary's refusal to attend appointments and her probable concern for her son are hints of this family's culture but this review can only hypothesise on how influential these factors were on her decision making.

There are different views and perspectives on the subject of neglect and self-neglect and work is underway by the safeguarding partnership to create a multi-agency protocol to enable a common understanding of this and agree on an appropriate and proportionate multi-agency response to concerns.

Were the views of Mary established and clearly understood?

Partners agree that when professionals interacted with Mary, she was listened to, and her wishes followed and it would appear that her family did the same. All those involved with Mary respected her wishes, but it is difficult to establish if the risks posed by her non-attendance at clinics for follow up and investigations could have been made explicit to her. Mary resolutely adhered to her wish to stay at home, to the extent that it was difficult for the ambulance service to persuade her to go to the hospital. The extent of that resolution is made explicit by the fact that she died of undiagnosed terminal cancer only a few hours later and so must have been in considerable pain. This serves to demonstrate her resolve and helps to understand how difficult it may have been for those near her to persuade her differently.

Partners, including the hospital and the CCG, when contributing to this review have recognised the need to pursue non-attendance at appointments more creatively and to be

persistent with their line of enquiry when they are interacting with the person and, at the very least inform them of the risks of non-attendance. Policies on this have been revised during the process of this review.

Learning

The voice of the user is important as it informs us about their wishes, views and feelings and may reveal the risks their choices might pose to them. It is important to understand their views but it is equally important to ensure their views are well informed about any risks posed by their decision making. Persistence, tenacity and skill are required to follow up people who choose not to attend appointments to encourage them to attend and inform them of the risks of not attending. It is also helpful to be mindful that there may be other professionals working with the person and an enquiring approach might help find them, so that information and risks can be shared. This is facilitated by the Slough Safeguarding Partnership Multi-Agency Risk Tool (MART link will be here).

Was her mental capacity robustly assessed, clearly documented and regularly reviewed?

The GP had no concerns around Mary's mental capacity and the assumption that she had mental capacity throughout appears to be correct. Mary talked about having a problem with memory loss and the GP suggested she attend the memory clinic but she declined this. Memory loss does not necessarily imply a compromised mental capacity, and this would not give rise to a challenge to the assumption of above. Her memory loss may have been a factor in her non-attendance at appointments, but this cannot be confirmed. It is not possible to evaluate why Mary did not seek help in her final months, weeks and days. In any event, the decision on whether to take up the offer of services was always Mary's.

There was therefore no information to suggest that Mary's mental capacity was in question and so there was no trigger to initiate a mental capacity assessment.

Learning:

The decision on whether to take up the offer of a service is always made by the person concerned. Non-attendance at appointments, even when there are risks does not suggest a compromised mental capacity. In terms of the Mental Capacity Act, a combination of factors such as memory loss and non-attendance at appointments might cause professionals to assess whether mental capacity (decision specific) is of concern or whether the decision can be assessed as an 'unwise decision'. The GP did this when they followed up on Mary's non-attendance as described below.

Did those living with her get support? Did they see themselves as carers who could get help? Did professionals identify family members as carers?

The review has established that Mary lived with her husband and that her son visited frequently. Professionals observing his relationship with his mother are likely to name her son's role as that of carer. However, from what we know of him, it appears that he is less likely to have seen himself as such and is more likely to see himself as a son looking out for his ageing parents. Her husband, like many partners, is similarly unlikely to see himself as a "carer" as this is intrinsic to the relationship he has with her.

Learning:

Reaching "unknown carers" is a perennial problem as several SAR's nationally and locally have identified. Campaigns to raise awareness about support available to "unknown carers" nationally and regionally have had positive impact but are difficult to sustain. If this is a

recurring issue, then a new solution needs to be explored, using language and approaches that will resonate more directly with people in these situations. The role of “carer” is seen by families as intrinsic to their relationship. The professionalisation of one aspect of an intrinsic and intimate relationship is difficult for families and professionals to navigate. Families have difficulty in understanding that they deserve help without stigma, and professionals have difficulty in reaching them with this message. Campaigns tend to target those who are in these caring roles, and this means that the onus is on carers to seek help. If they are experiencing the inner conflicts explained above, it is difficult for them to accept that the message applies to them. Although research shows that campaigns do have a positive impact as they generate referrals, they are limited by these issues and need to be supported by sustainable measures at practice level.

In addition to regular campaigns, awareness raising needs to be incorporated into regular practice in statutory and voluntary agencies so that they can be instrumental in helping those they reach. It also needs to be in media that is accessible, and this sometimes involves handing out old fashioned leaflets and cards to individual people and offering to make a referral. We need to find ways to shift the onus from carers to seek help by supporting all professionals to recognise carers and advise them. One phone call can trigger a range of support and make a real difference to their lives.

The intrinsic nature of the carer/caring relationship assumes that the person cared for is also comfortable with a change to dependency and this needs to be considered.

Were there missed opportunities to instigate partnership working that might have helped Mary?

Partners have identified above that non-attendance at appointments could be a trigger to instigate partnership working and this is discussed above.

Were there examples of good practice?

This review identified the importance of primary care services, in particular the GP in pro-actively making efforts to encourage Mary to attend her appointments. It was noted during the analysis workshop that the GP provided a person-centred approach and followed up Mary’s non-attendance at appointments. Mary’s wishes and her voice were listened to and respected. The Hospital provided Mary with sensitive skilled end of life care.

What needs to change:

Points for practice 1: When people do not take up services.

Practitioners and their managers working with people who do not accept the offer of services should persist in their efforts and consider the possibility that broader family influences may be affecting individual’s decision making.

Listening and respecting the views of the person are important to assist in this understanding. It is equally important to ensure their views are well informed about any risks posed by their decision making.

Making Safeguarding Personal should be about understanding the person, not from the perspective of what can or cannot be done by an individual provider but

considering what life is like for them and understanding the reasons for their decisions.

What needs to be done:

- All partners need to commit to promoting this learning in their own agencies to enable a bespoke person-centred approach that explores why a person refuses what is available and/or recommended for them
- The safeguarding partnerships' safeguarding adults advancing safeguarding practice group is one of the quality assurance arms of the partnership quality assurance functions and should ensure that partners account to this group on the impact of their actions to deliver the above messages to practitioners.
- The same group should include this issue in planned multi-agency case audits.

Monitoring impact:

Partners accounts to the advancing safeguarding practice group will show impact in each of the agencies.

Multi-agency audits will establish the extent of professional understanding of these issues in practice.

Points for practice 2: Reaching people who care for their relatives.

Caring for relatives can be seen as intrinsic to family relationships and because of this it is difficult for those people who care for their relatives to see themselves as in need of help without stigma. Equally professionals find it difficult to reach these people for similar reasons. Sensitive support needs to be provided to the individuals who need care to help them understand that their relatives may also need help.

What needs to be done:

A sustainable communications arrangement should be set up by the safeguarding partnership communications group to reach out regularly and routinely to the professional, (including the voluntary sector) and general community. This needs to be supported by communications tools, such as simple cards or leaflets for practitioners, especially GP's and those in the voluntary sector. These could be used to encourage people in these situations to get the help they need.

Monitoring Impact:

The impact of this is difficult to measure, but a successful campaign delivered regularly and repeatedly, is likely to generate new referrals for carers assessments and this could be a performance indicator.

Next steps:

Once signed off by the SARP and the SLG, the actions in this report will be followed up by the groups it refers to. The SARP will request accounts from partners and sub-group chairs on progress made 6 months following publication.