Significant Case Review

P19

Executive Summary Report

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ON BEHALF OF ANGUS ADULT PROTECTION COMMITTEE

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FOREWORD

As Independent Chair of the Angus Adult Support & Protection Committee (AAPC), I very much welcome receipt of this Significant Case Review report which has been prepared in respect of Adult P19.

This Report sets out a number of key Findings and subsequent Recommendations, all of which are fully accepted by the AAPC. The AAPC will ensure that all of the Recommendations will be addressed and actioned and that the progress of this work will be closely monitored to ensure that relevant progress is made as quickly as can possibly be achieved. It will also be important to ensure that the good practice identified in the Report is disseminated as widely as possible to all key professionals.

It is absolutely vital that the learning identified in this Report is incorporated into amended policy and practice. This will ensure that vulnerable adults in Angus, as Adult P19 was, are consistently offered high quality levels of support and protection to address their safety and thereby mitigate the risk(s) that exist in their lives.

The outcome of interventions in the lives of vulnerable adults must be that their well-being and quality of life is enhanced, and the implementation of this Report's Recommendations will go a significant way to deliver on this important objective.

The involvement of a wide range of Professionals who work in the arena of Adult Protection in Angus and across Tayside has been very welcome and their positive contribution to the work of the Review Team has been very much appreciated.

Introduction

This Executive Summary presents the main findings of the Significant Case Review (SCR) in respect of Adult P19. Names have been changed to protect the identity and confidentiality of the family. This Executive Summary has been developed by the two Independent Reviewers and reports on the findings from the Significant Case Review.

The findings of this review have relevance both locally and nationally and the Angus Adult Protection Committee (AAPC) would encourage the findings of this SCR to be used widely to progress improvements as they offer a view on a complex system from the perspective of a vulnerable adult with complex health and social care needs.

Why this case was chosen to be reviewed

Adult P19 died in December 2018 at the age of 50 as a result of Disseminated Malignancy (a condition in which cancer is spread widely throughout the body). There was significant involvement with a number of services in the months leading up to death. P19 was identified as an 'adult at risk' in August 2018.

Following P19's death, the Angus Adult Protection Committee (AAPC) received a request for consideration of an Significant Case Review (SCR) on the grounds that

adult P19 was in receipt of services, was subject to an Adult Support and Protection Plan and that P19's experience of services provided an opportunity to learn and improve how we work. Following completion of an Initial Case Review (ICR), AAPC agreed an SCR was necessary to explore in depth the circumstances of P19's death and the time and events leading up to it.

The SCR Lead Reviewers sought contributions to the review from appropriate family members and kept them informed of key aspects and progress. P19s family reflected that P19 was 'popular and good looking in their younger days', kind, caring with a 'wicked sense of humour'. P19 was also noted to be a very proud person who took great pride in their personal appearance and was always smartly dressed.

The Facts

- P19 died at the age of 50, having had significant involvement with services in the months leading up to their death. The cause of death was recorded as disseminated malignancy (advanced cancer). P19 undertook a bowel screening kit in October 2017, testing positive. At the time of death, P19 was emaciated, weighing only 42 kgs and with a BMI of 14.2. Multiple Sclerosis (M.S.) had been diagnosed in December 2014.
- There was significant involvement from 19 services across a wide range of agencies and organisations during the 4 months prior to death.
- P19 had also been known to a variety of services prior to this, some of which had had significant involvement with P19 over a number of years whilst others were involved on a more ad-hoc basis for specific interventions.
- In the last week of P19's life P19 was no longer drinking alcohol. P19 was eating and drinking very little and staff would offer food and fluids during support visits. The conditions of the house were described by staff as "horrendous ". P19 was incontinent of both faeces and urine and would be heavily soiled, creating a very unsanitary living environment. Carpets and furnishings would also be heavily soiled, and staff would attempt to clean this up. P19 was in a lot of pain and unable to mobilise. P19's skin was very sore and peeling due to the level of incontinence.
- 2 days before P19 died, staff had to use a basin to undertake personal care as P19 is unable to mobilise to reach the bathroom. By this point, P19 is constantly soiled with faeces, has poor mobility, sore skin, is in a lot of pain and is eating and drinking very little, not getting enough fluids and often can't sleep.
- Staff had to wear white suits, gloves, aprons, shoe covers, oversleeves, protective eye gear and masks, whenever they entered the house. Despite the PPE, staff would find the smell unbearable - some staff would be physically sick, and some were in tears at P19's situation.
- Managers of the care at home provider made the decision that they could no longer continue to provide support due to the effects the situation was having

on staff and this was discussed at a core group meeting 6 days prior to P19's death. The day P19 died on 19 December 2018 was the last day that the care at home provider was providing support. At this point in time there was no contingency plan in place although a variety of options were being explored.

- All nursing homes in Angus and Monifieth had been contacted but there were no vacancies available. A request to community alarm for a planned service had been made but they had no capacity. A hospital admission had been attempted and refused. Care Managers were planning to explore care at home overnight support, care and nursing home vacancies in Dundee and input from the enablement and response team.

Findings and Analysis

Research Question 1 - In respect of P19, to what extent was the information held by Agencies shared appropriately within that Agency and with other partner Agencies?

Information Sharing and Recording Systems

Generally, information sharing was found to be disjointed, often insufficient and sometimes not accessible to other key professionals. This resulted in some professionals being unsighted on key information which impacted on decision making. Information sharing appeared particularly poor at times of transition such as hospital discharge, entry to respite care and transferring from homelessness support services to homecare. There were occasions when information was shared and no action or follow up occurred.

Health Service Involvement

Co-ordinated discharge planning did not happen, and key professionals such as district nurses, were not included as part of any discharge procedures/discussions neither was their input requested. There was no health professional co-ordinating any health input or monitoring health needs. Community services received limited health information following discharge from hospital.

Transfer of Cases

Some service areas within the AHSCP have no system in place that provides assurance that a case referral made from one service to another has been received or to inform them that the required support has commenced, prior to current service support ending and the case being closed.

Findings

- There are a variety of different recording systems across various sectors of the health service, between social work and health and within housing services resulting in not all relevant information being accessible to those

that need it, when they need it. This is a barrier to effective information sharing which contributed to inadequate information sharing between some agencies and resulted in some key professionals being unsighted on key information which impacted on decision making and robust risk management.

- The quality of record keeping was found to be poor across several service areas and this did impact on key professionals having access to the information required.
- Had effective discharge procedures taken place and a referral to district nurses been made at the point of discharge, P19 may have been placed on the caseload for the district nurses and input may have resulted in access to a range of interventions and support such as palliative care.
- There is no evidence to confirm that P19 was discussed at an MDT. If this had happened, then unmet health needs may have been identified.
- There were no records available from Acute Services although a system is now in place where written electronic referrals are received by Acute Services from GP's.
- P19's service input ended, and the case was closed by service 1 following a referral for ongoing support to service 2. This support was not provided by service 2 and service 1 were not aware of this. This resulted in P19 receiving no support for approximately 4 months.

Good Practice

- Good team working and communication between the care management teams and the care provider.
- Good quality record keeping was identified across several different service areas such as the AHSCP respite service, the care at home provider and NHS Tayside Inpatient Detox Unit.

Recommendations

There are 8 recommendations related to research question 1 which can be viewed in the main report. These include enabling interoperability and access of recording systems, effective information sharing at points of transition and reviewing hospital discharge procedures.

Research Question 2 - Determine the extent to which decisions and actions were person centred.

Bowel Testing and Diagnosis

Changes in P19s bowel habit were first noted in January 2017 but a formal diagnosis was still outstanding at the time of P19s death in December 2018. Throughout this time, a number of appointments were offered which P19 did either not attend or was unable to attend.

Professionals appeared to have 'diagnosis paralysis' where they were pre-occupied with the need for a diagnosis of cancer to initiate access to palliative care. P19 was not identified for a palliative care approach and the impact of this was significant in the latter stage of P19s life which included significant pain and an inability to mobilise.

Changes in P19s bowel habit resulted in an inability to control bowel movements, and the amount of faecal incontinence experienced by P19 as a result of bowel cancer was highly unusual and required further assessment and management. This did not take place and led to reduced dignity for P19 including enduring uninhabitable living conditions, as well as limiting the available options for 24 hour care.

Compliance with medication was identified as an issue for P19 and a venalink had been arranged but was unsuccessful. No other methods of supporting medication compliance were explored. P19 was noted to experience significant pain but was being managed with Paracetamol and Codeine. Health care professionals involved in P19's care appear to have failed to recognise that they were dying.

Primary Care

The service involvement to P19 was significant with many agencies involved in the months prior to death. However, not all key professionals were involved in decision making, planning and support or involved at the right time. District Nurses were involved with P19 for specific tasks but P19 was never referred to the District Nursing service or placed on their caseload.

Secondary Care

P19 was considered 'hard to engage' due to some appointments and follow up investigations being missed. This was seen as an indication of informed choice being exercised rather than possibly evidence that something was wrong which required intervention. There was a lack of clarity across the agencies as to what protocols and procedures exist when a person gets lost to follow up treatment.

The escalation process used by GPs when they are seeking hospital admission is viewed at times as person dependent and built on relationships and influence rather than process driven and requests are often refused. Medical staff acknowledged that there is a current gap in clinical pathways for urgent out-patient appointments where there is possibility of cancer and other conditions that requires further investigation in a shorter time period rather than the usual referral process.

Falls Management

Having a diagnosis of MS increases an individual's risk of falls due to the changes in muscle strength, muscle tone, co-ordination and gait. In addition to MS, P19 had a number of other risk factors including history of binge drinking, was not eating regular meals, was experiencing pain, significant weight loss and altered bowel habit.

The Falls service received a referral from the Scottish Ambulance Service in June 2018, however P19 did not engage despite numerous attempts by the service and P19 was therefore discharged from the service, with no input. Despite P19 experiencing a number of falls both within and out with the home setting between August 2018 and December 2018, the Falls service received no further referrals or notifications regarding P19 despite a number of falls being recorded as well as a fall resulting in admission to hospital and a surgical procedure.

Findings

- P19 had a right to treatment to meet needs regardless of whether a formal diagnosis was available. The District Nursing service should have progressed with a holistic assessment and plan for P19s physical, emotional, social and spiritual care needs, along with an anticipatory care plan to incorporate Just in Case Medications for symptom management.
- The health care team failed to recognise and reach an agreement that P19's death was expected and imminent. This resulted in P19 dying with uncontrolled physical, emotional, social and spiritual symptoms. P19 died with no dignity and none of their needs anticipated or managed.
- There was a lack of a holistic person centred approach to care and an absence of anticipatory care planning (or thinking ahead) which would have provided planning to ensure P19 had the right person to do the right thing, at the right time, facilitating shared decision-making and person-centred care in the appropriate setting.
- Whilst P19 often refused interventions and support to meet health and personal care needs, interventions failed to take a person-centred approach with a failure to see the person which resulted in missed opportunities to work with P19.
- Despite a number of agencies being aware of a number of falls, no referral was progressed to the locality Falls service in line with the falls pathway to ensure a person-centred approach to falls and fall prevention.

Recommendations

There are 10 recommendations related to research question 2 which can be viewed in the main report. These include reviewing the process for referring to District Nurses, ensuring services support integrated working and the involvement

of the correct professionals/agencies and considering a pathway for admission to an acute medical hospital setting for people with chronic long-term issues where wider acute medical problems cannot be managed within primary care settings.

Research Question 3 - To what extent did one Professional/Agency have a lead role and hold responsibility for P19 and their Protection Plan; to monitor what was being achieved, any gaps in assessment, planning and decision making and associated risks?

Adult Support and Protection (ASP)

Police progressed a timely VPR and this was actioned, however it took 6 days for the referral to be allocated to the AIDARS service and a further 7 days for AIDARS to undertake the first home visit – a total of 15 days between Police identifying home conditions and the first home visit happening.

A case conference was held in early September 2018 and identified P19 as an adult at risk of harm. Following this case conference, five core group meetings were held. Not all the right people were involved in the ASP process at the right time and this would have benefitted from a wider group and co-ordination of a more comprehensive multiagency risk management plan.

Membership of the core group meetings did not involve all the key professionals required to take action in relation to the presenting issues and concerns and this contributed to the lack of progress and accurate information. Whilst a number of benefits were noted from the ASP process, the core group meetings did not effect all the changes that were required to mitigate the identified risks.

There was a lack of clarity in relation to authority and decision making at case conference and core groups meetings. It was the view of the majority of professionals involved in this case that adult protection processes did not make a difference to P19's quality of life prior to death. Whilst chronologies and risk assessments were in place, these were not reflective of all the relevant information from all agencies and were not up to date.

It was difficult to determine with any accuracy if all relevant staff across both health and social care had undertaken adult protection training and at what level.

Escalation, Professional Accountability and Decision Making

Lines of professional accountability and decision making were a confusing picture. Understanding of personal accountability varied greatly across services. Some services understood the accountability they had yet were unable to find a way to meet this. Other services felt that accountability lay elsewhere.

Staff were unclear of lines of accountability, roles and authority to commit resources and assign personal responsibility between people in authority, ASP case conferences and the role and authority of the Angus Adult Protection Committee.

Escalation failure was identified for 9 services throughout this review. Where escalation did happen, many concerns remained unaddressed. Avenues for escalation such as multi-disciplinary meetings or ASP case conferences were not utilised to escalate concerns and aid decision making.

Findings

- There was uncertainty in relation to roles, authority and decision making at the ASP case conference and core group meetings which meant that not all required actions were identified and followed through to support and protect P19.
- Difficulties remain in securing attendance and information at ASP meetings from various services and organisations. There were missed opportunities to engage health professionals in the ASP process.
- Lines of professional accountability are unclear within different services. There is no clarity of how professional accountability works across different organisations. Where escalation did happen, it did not make a difference.
- Although good team working was evident between staff and case workers, having 2 case holders responsible from 2 different service areas (rather than one case holder from one service area having lead responsibility), relies on collaborative working happening at all levels of management within and across services in a consistent way. It also relies on a shared understanding of escalation, professional accountability and decision making. This did not happen in relation to P19. This meant that the casework, concerns, risks and related decisions did not attract the attention or oversight of Senior/Middle Managers, even when a high risk of death had been identified.

Good Practice

- There is now an identified Police representative for Adult Protection within Angus which provides consistency and continuity from Police Scotland.
- The care provider escalated concerns regularly and repeatedly, comprehensively specifying what these concerns were and providing evidence for them, based on their daily engagement with and observations of P19.

Recommendations

There are 14 recommendations related to research question 3 which can be viewed in the main report. These include having a robust system in place for monitoring ASP cases and raising these with Team Managers in supervision, ensuring that membership of core group meetings include health professionals and reviewing the learning, development and quality assurance opportunities in place to support staff to develop consistent practice in producing adult protection plans.

Research Question 4 - How effective are the current processes for requesting a Capacity Assessment within NHS Tayside and how these processes are applied in practice.

Capacity Assessments

There are large variances across Tayside in relation to accessing a capacity assessment. There is varying understanding between professionals regarding the process of obtaining a formal capacity assessment. Professionals described 'going around in circles' in terms of trying to access an assessment of capacity for P19 and in obtaining clarification on the formal assessment process and requirements for this.

There are difficulties for people accessing a capacity assessment generally but specifically for people with a physical disability who do not access a psychiatry service. People with a physical disability do not have a pathway in place for accessing capacity assessments; however, there is no pathway in place for any service.

There is a lack of knowledge within acute services in understanding capacity and their responsibilities in caring for patients who require capacity assessments as opposed to consent to treatment. An assessment of capacity was requested whilst P19 was an inpatient in hospital and abstinent from alcohol. The hospital informed professionals that an assessment of capacity had been undertaken and that P19 did have capacity. Hospital records note that it was not an assessment of capacity but Informed Consent for medical treatment that was assessed and documented. There are misunderstandings within acute care of what a capacity assessment is, and health professionals often see AWIA as specifically relating to S47 consent to treatment.

An AWIA decision making meeting was held for P19, where it was unanimously agreed that a move to a care home would be in P19's best interests and they could move to a 24-hour facility under Section 13ZA, on the understanding that an application for Welfare Guardianship was made to safeguard and protect P19. At this point, two medical reports should have been requested for the application of guardianship to begin.

However, despite P19 initially agreeing to the move, they later changed their mind therefore 13ZA could no longer be used as all parties, including the person, need to agree to the proposed care. Due to the fact that 13ZA could no longer be utilised, a

further AWIA meeting was arranged. However, this meeting was cancelled after the ward advised that the Consultant Psychiatrist had assessed P19 as having capacity. As a result of this, the AWIA could not progress. The consultant had, in fact, not undertaken an assessment of capacity but a S47 consent to treatment, as highlighted above.

Despite the level of concerns from professionals in relation to P19's capacity, no one challenged the capacity assessment decision from the hospital. No one requested a copy of the capacity assessment or any detail of the assessment that would assure them that it had taken full account of P19's personal situation. Practitioners did not seem to be aware that when there is a disagreement between clinicians regarding an adult's capacity, that a 3rd medical opinion can be sought.

Capacity and Alcohol

Professionals were unclear about P19's capacity. Several agencies did question whether P19 had capacity and concerns had been raised in relation to P19's short-term memory and use of alcohol, which could have impaired long-term capacity and decision making.

Whilst there was no diagnosis of mental disorder in P19's case, there was evidence in reports which indicated that there were occasions when P19 was sober that they displayed difficulties in concentration, anxiety, depression, memory and confusion. This could be indicative of Alcohol Related Brain Damage (ARBD)although no reference or mention of this being formally considered for P19 was found throughout the course of this review.

P19's decision making and ability to effectively care for themself was potentially influenced by their anxiety, depression and alcohol use. It appears that P19's capacity would regularly fluctuate. This makes cases like P19 complex in terms of the decisions that professionals have to make. However, there was no record of ARBD having been considered.

Professionals were advised from medical staff that they had to wait for P19 to be free from the influence of alcohol to have a capacity assessment undertaken. Locally there were varying opinions of how long a period of time P19 had to be abstinent from alcohol before a capacity assessment could be undertaken.

As a consequence, staff often felt disempowered and assumed that there was little that they could do to intervene, particularly when P19 was still consuming alcohol. This presents a challenge for agencies to deliver effective intervention as, on occasions, they are unable to wait for the opportunity to assess the person when sober.

Findings

- No one person took responsibility for obtaining a capacity assessment.

- There were numerous attempts to identify someone to undertake a capacity assessment for P19 and varying understandings of who should/could do this. This resulted in no assessment of capacity being undertaken.
- There is no clear pathway for people to access an assessment of capacity, including people with alcohol issues. This currently appears to be dealt with on a case by case basis.
- Taking into account the complexities of undertaking an assessment of capacity when P19 was often under the influence of alcohol, nonetheless, there were opportunities when P19 was alcohol free and a capacity assessment was not undertaken.
- No one requested a copy of the "capacity assessment" completed by the Consultant or any information that would provide assurance that it had taken full account of P19's ability to safeguard themself.
- Professionals who assessed P19 did not appear to have an understanding of the link between prolonged alcohol use and impaired mental capacity. ARBD was not assessed and thiamine treatment was not considered. Professionals appeared to take poor co-operation and non-engagement with treatment as indicative of a conscious, informed choice, and therefore made little effort to pursue assertive treatment or consider the use of relevant legislation.

Recommendations

There are 6 recommendations related to research question 4 which can be viewed in the main report. These include developing a clear pathway for accessing an assessment of capacity, developing a protocol for sharing the outcome of a capacity assessment with the care team, ensuring appropriate AWIA education and training is provided to relevant acute and primary care services and providing guidance and training for staff around the relationship between alcohol, care, capacity and ARBD.

Research Question 5 – To what extent is Self-Neglect understood across the multi-agency Adult Protection partnerships and wider Adult Protection providers?

<u>Understanding Self-Neglect</u>

The term 'self-neglect' covers a wide range of behaviour and P19 displayed a number of characteristics often associated with self-neglect and these included:

- availability of adequate clothing which was evidenced on admission to the detox service whereby staff noted P19's clothes were too big due to weight loss

- living in unclean conditions which staff described as 'squalid' and included faeces in a number of rooms

- failing to care for self which resulted in a decline in health and wellbeing

- poor diet and nutrition

- non-compliance with prescribed medication

- refusing community supports

- non-attendance at appointments leading to untreated medical conditions

Staff noted that P19 did not appear to have insight into how unsanitary conditions within the home were. Managing the balance between protecting adults from self-neglect against their right to self-determination is a serious challenge for statutory services and partners along with other people involved in the person's life. Balancing choice, control, independence, and wellbeing calls for sensitive and carefully considered decision-making. Dismissing self-neglect as a "lifestyle" choice is not always an acceptable solution in a caring society. On top of this, there was the question of whether P19 had the mental capacity to make an informed choice about how they were living and behaving and the amount of risk this created.

Staff Impact

The physical, emotional, and psychological impact of seeing someone die in front of their eyes with no palliative care in place, no pain management, no dignity and feeling that nothing was being done despite their repeated escalation was clearly a traumatic experience for staff of the care at home provider. Staff shared they felt helpless and some have required ongoing counselling and support. As a result of this there may have been a failure towards the moral, legal and ethical responsibilities for the wellbeing of these staff.

Due to the severity of P19s living conditions which staff were exposed to, staff were advised of the need to wear full PPE protection on entering the house due to the health and safety risks this posed for them. The decision by the care at home provider to withdraw support was a very difficult one to make and is not a situation that is common. The reviewers noted that the service did not want to be in the position whereby they felt the need to withdraw support but made that decision based on the impact the situation was having on their staff.

Values and Behaviour

Some services felt that their 'voice' was not being heard because of their position or job role and this was possibly because they are perceived to be of a lower grade within the wider hierarchy and as such they felt their expertise and experience was not recognised and that their views not sought or valued by other professionals involved.

Stigma Relating to Alcohol Issues

The prominent position that alcohol has within our society means that professionals involved in planning and delivering services may well be influenced by some of the prevailing attitudes and perspectives towards the use and abuse of alcohol. There may be feelings of pessimism about the possibility of rehabilitation or recovery; or that the individual is undeserving of help having brought the problem on him or herself; whilst others may feel reluctant to make value judgements about someone else's drinking. It is likely that individual as well as institutional attitudes play a role here and the importance of staff being aware of their own values, beliefs and prejudices is paramount.

It is apparent that the assessment, planning and delivery of care by some professionals involved with P19 was adversely affected by prevailing critical attitudes towards people who abuse alcohol.

Non-Engagement and Duty of Care

Services failed to recognise the range of complex factors affecting non-engagement in the context of vulnerability, which had an impact on P19 accessing the support required when it was needed. There is no evidence that these services considered whether P19 had the capacity to understand their welfare needs, make decisions about accepting interventions or had the ability to engage in the way services demanded e.g. travel to and attend clinic appointments.

A variety of services offered P19 services but failed to pursue P19's refusal to engage. There is no evidence that they considered whether P19 had the capacity to understand their welfare needs or make decisions about accepting interventions.

Housing

Regular inspection of houses doesn't ordinarily take place to pick up issues of self-neglect at an early stage. Housing were therefore unaware of the uninhabitable living conditions P19 was found to be living in. A recent restructuring of the housing service has led to smaller patch sizes for Housing Officers which should enable more regular inspections of those tenancies, where housing is aware a vulnerable person resides. Sufficient flexibility now exists within the current system to support this approach.

Housing had no temporary accommodation available for P19 when found by police, in a crisis situation in August 2018 and no other options were offered. The Physical Disability Service Leader identified a potential option and liaised with housing to secure this, resulting in temporary accommodation being sourced. This was the temporary accommodation that P19 remained in, until their death in December 2018.

P19 had been awaiting allocation of a ground floor property due to a physical deterioration caused by Multiple Sclerosis resulting in difficulty accessing the outside stairs to the property. This process commenced in April 2017 and at date of death on 19 December 2018, P19 was still living in temporary accommodation with outside stairs and awaiting allocation to a ground floor property. This had been delayed for some time due to historical housing debt. The housing allocation policy includes a

discretionary allocation procedure for special cases, for example people who are terminally ill and unlikely to be rehoused within existing priority processes.

Housing have now introduced the Housing Adaptations Joint Working Policy, which sets out joint working arrangements to ensure that all options to meet a person's needs are explored from the earliest opportunity, including the suitability of the property to meet the medium to long term needs of an individual and the opportunities for rehousing. This includes a section covering the role of joint case review meetings to ensure cases are being monitored and reviewed consistently across the 3 housing teams, in partnership with the Occupational Therapy service.

P19's circumstances highlight the importance of these case review meetings in monitoring applications where there is an unmet medical / adaptation need and provides the opportunity to identify any changes in circumstances or barriers to rehousing (e.g. rent arrears) so these can be addressed more proactively.

Respite Provision

The majority of respite provision in Angus is registered with the Care Inspectorate to provide care to people over 65 only. Some providers do not feel they can adequately meet the needs of those under 65 within their current provision.

P19 was provided with respite care in a provision that was for older people. In order to accommodate P19, this provision firstly had to progress a change of registration with the Care Inspectorate in order to be able to support someone under the age of 65. This was progressed efficiently and quickly, however staff at the provision felt it was an unsuitable environment for P19 and they could not adequately meet their needs due to age, complex needs and the presenting needs of the other service users.

Findings

- Staff did not fully understand P19s circumstances and what led to the extent of the self-neglect. There was a failure to fully recognise and understand the relationship between alcohol misuse and self-neglect. Additionally, staff did not know what to do and where to turn for advice and guidance and at that time, there was no available guidance to assist staff.
- The reviewers recognise the efforts that staff of the care at home provider went to in their efforts to support P19 and that included their persistence to escalate concerns to health professionals and managers. Staff were determined and resourceful and they continued as long as they could despite the impact the situation was having on them.
- Assumptions were made by services about alcohol misuse being the cause of P19's physical ill health and non-engagement. Staff from various agencies encountered attitudes and stigma relating to people with alcohol issues from other professionals.

- P19 was offered services, but many services failed to pursue non-engagement.
- No regular inspecting programme is in place in relation to the inspection of properties. Had this been in place for P19, self-neglect and uninhabitable living conditions would have been identified at a much earlier stage and P19 would not have had to live in the squalid conditions they were found in, for the length of time that they did.
- There is sufficient flexibility already in the housing allocation policy to deal with vulnerable tenants and to have addressed P19's situation, although this flexibility appears to not have been appropriately used in this case.
- It is difficult to meet the respite needs of younger people within an older people's respite environment due to the different lifestyles that people lead at different chronological ages. Staff felt they were not adequately trained to meet P19's needs and were only able to meet basic needs. Alternative respite options were very limited.

Good Practice

- Angus APC arranged for the National Protection Co-ordinator (NAPC) to deliver a learning session to a wide range of practitioners on self-neglect in Nov 2019.
- The Physical Disabilities Service Leader displayed good practice in identifying an opportunity for temporary accommodation for P19 at the point when housing said they had nothing available. Housing then progressed this accommodation quickly.
- Housing provided a new bed and bedding for P19 in preparation for P19 returning from an inpatient stay following operation on dislocated shoulder.
- Good practice was identified in displaying flexibility in changing the Care Inspectorate registration category quickly to enable P19 to access the respite service.
- Staff at the respite service evidenced commitment and effort to provide good quality care to p19 albeit they felt they were not adequately trained to do so.

Recommendations

There are 14 recommendations related to research question 5 which can be viewed in the main report. These include additional learning opportunities on understanding and dealing with self-neglect, training and awareness in relation to alcohol use, guidance in providing safe and appropriate care for individuals who

are difficult to engage, progressing plans to develop adequate respite provision for people under 65 and providing assurance to staff that a range of improvements will be implemented to decrease the chances of such a situation happening again.

Research Question 6 - To what extent and detail should information be provided to COPFS when someone who was subject to Adult Support and Protection measures dies to ensure that COPFS are able to assess the circumstances surrounding a death in those circumstances and direct further investigation and enquiry.

Notification and Information Sharing

The Sudden Death Report received by COPFS from Police Scotland did not specify that P19 was an Adult at Risk and was subject to Adult Support and Protection (ASP) procedures at the time of death. The Report did not include any detail of the risks that had been identified for P19 nor the issues relating to mental capacity. As previously highlighted, one reason for this was because Police were unaware that P19 was under formal Adult Support and Protection procedures and had received no notification of this.

In line with the reporting process, the GP provided information to the sudden death report and although P19's GP was aware that P19 was subject to ASP procedures, the GP did not highlight this to the Investigating Officers or directly to the PF.

Had COPFS been aware of the concerns/risks that were in place at time of death, then it is likely that a more detailed Post-mortem would have been requested than that which was actually undertaken. This may have subsequently led to further enquiries.

Issues were highlighted in respect of the Police being aware of who is actually subject to Adult Support & Protection procedures and Police Officers attending Adult Protection Case Conferences and Reviews. This has resulted in an agreement that reports will be forwarded to Police Scotland on a monthly basis containing the details of all adults who have become subject to Adult Support & Protection and this will also include when a person who has been subject to those procedures is no longer deemed an adult at risk. Police Scotland will ensure its records are kept updated using their own internal processes.

Findings

- The sudden death report failed to include key information that was later identified and shared with the COPFS. Had this information been available to the COPFS at the time of P19s death, a more detailed post-mortem may have been warranted.

- The current documentation in use across Scotland (both within hospitals and primary care) does not specifically ask whether the person who has died suddenly was or may have been subject to formal adult support and protection procedures and there is a lack of best practice in reporting sudden deaths when adult protection may be relevant.

Recommendations

There are 4 recommendations related to research question 6 which can be viewed in the main report. These include clear guidance for GP's and police detailing the information that sudden death reports should contain.

Research Question 7: Did all Agencies exercise their full legal Powers to ensure the safety and wellbeing of adult P19?

Use of Legislative Powers

There was evidence that the use of The Adults with Incapacity (Scotland) Act 2000 was considered for P19, in terms of the AWIA decision making meeting that was held, the decision to use section 13ZA to facilitate P19 moving to a care home and the decision to progress welfare guardianship. Due to P19 changing their mind about agreeing to a move to a care home, 13ZA could no longer be utilised. The AWIA process was also stopped after the hospital ward advised that the Consultant Psychiatrist had assessed P19 as having capacity. As a result of this, the AWIA could not progress. The consultant had, in fact, not undertaken an assessment of capacity but a S47 consent to treatment, as highlighted above. There was no evidence that the use of other legal powers had been considered for P19.

The use of the Mental Health Act was not considered. This may not have been appropriate for P19 as the 5 criteria required would not have been met to satisfy this.

A short-term detention order (if satisfied there is a mental disorder) would not have been appropriate to use as it is only applicable to treat the individual rather than to keep them out of harm's way.

Professionals displayed differing understanding/interpretation of the Mental Health legislation, particularly in relation to assessment of capacity.

There is no evidence that powers under the Adult Support and Protection (Scotland) Act 2007 were considered in relation to P19.

It may have been worth exploring if an assessment order would have facilitated the required capacity assessment for P19 and the progression of welfare guardianship, as well as allowing for a formal diagnosis to inform treatment/support as P19 was an adult at risk and was asking for help. Whether this is how this legislation could or should be used would also be relevant to consider in terms of whether legislation should be required to provide an assessment of capacity. Professionals also

appeared to lack knowledge and confidence around the use of Assessment Orders as they are not frequently used.

It could be argued that a Removal Order could have been applied to P19 to remove from the harmful living environment to a place where the care and treatment required could be received in a safe and sanitary environment. The difficulty in utilising this order would have been identifying and securing a suitable place to remove P19 to. The Sherriff has to be satisfied to the availability and suitability of the place to which the adult at risk is to be moved. The order only lasts for 7 days which would not have been enough time to use it to carry out an assessment of capacity and apply for welfare guardianship, following the required period of abstinence from alcohol.

A banning order would not have been applicable in this case as this order is used to prevent someone coming into contact with P19.

P19 had been asking for help and willing to co-operate with support/interventions on many occasions. P19 had also refused support/interventions on several occasions such as a second opportunity for respite care. Exploring the likelihood of consent in relation to these orders should have been undertaken.

Under Environmental Health regulations (EPA 1990) legislative powers available focus on statutory nuisance's out with rather than within a person's house and therefore would not have been applicable.

The only legal power available to housing would have been to pursue a Breach of Tenancy leading to eviction. In this case, that would not have been helpful or supportive to P19 and the preferred route was to identify support to improve living conditions.

In relation to P19, consideration should have been given to whether their human rights were breached in relation to Article 3 of the Human Rights Act 1988 which states:

'No one shall be subjected to torture or to inhuman or degrading treatment or punishment'.

The definitions of inhuman treatment covered by the HRA do not appear applicable to the lack of dignity and the degrading living conditions P19 died in.

However, it is also recognised that respect for the fundamental dignity of each and every person lies at the heart of human rights. People accessing health and social care support should not only have their rights recognised, but these rights should be realised. Human rights should be at the very heart of health and social care and embedded in practice. Not providing P19 with access to the right care and the right pathways, may have been a failure of practitioners and/or their managers to take positive action to protect P19's Human Rights.

Findings

- Not all legal powers available were considered and not all legal options had been fully explored within the ASP case conference and core group meetings. Demonstrating that all legal powers available had been considered, fully explored and utilised within the ASP case conference and core group meetings and that these discussions were recorded may have resulted in further actions/interventions being progressed to ensure the safety and wellbeing of P19.
- The only way that a safe, long term future could have been secured for P19 was through a welfare guardianship. This requires an assessment of capacity. Had P19 accessed an assessment of capacity, at the right time, then this could have been achieved.
- There was no evidence that the powers contained within the Adult Support and Protection (Scotland) Act 2007 had been considered and fully explored. If this had been done, it may have established whether an Assessment Order or a Removal Order would have been an appropriate intervention to protect P19 from further harm.

Recommendations

There are 3 recommendations related to research question 7 which can be viewed in the main report. These include amending local operating processes to ensure that a prompt is built into the core group meetings to consider the need for any of the legal powers available, review adult protection training to ensure that there is a clear focus on the use of emergency powers covered in the training and the introduction of training for relevant staff that provides an overview of the 3 Acts available to keep people safe.

Conclusion

P19 was recognised as an adult at risk and there seems to have been a genuine effort on the part of professionals involved to engage and support P19, albeit unsuccessfully to the point of being able to prevent death as a result of advanced bowel cancer. Clearly, there are lessons to be learned from the events that led to such a sad outcome and these have been reflected in the learning and recommendations within this report. In summary:

- This has been both a challenging case and a challenging process for some of the staff involved in supporting P19 and the emotional impact of the work and of the case outcome is understandably still being felt.
- P19 had an advanced bowel cancer and there is no one identifiable action that would have changed matters.

- The interconnection of diagnosis of bowel cancer, management of associated symptoms, capacity assessment, understanding the impact of alcohol use in identifying risk, delivering multiagency risk management plans together with P19 and information sharing all played a part on the overall experience and outcomes for P19.
- This case highlights a number of challenges that exist for professionals when the needs of an individual do not neatly meet the criteria for existing services and leads to unmet needs.