

Institution: Manchester Metropolitan University		
Unit of Assessment: C20 Social Work and Social Policy		
Title of case study: Improving and developing care for people using substances: supporting professionals and marginalised communities.		
Period when the underpinning research was undertaken: 2014 - present		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Sarah Galvani	Professor	2014-present
Sam Wright	Research Associate	2016-present
Gemma Yarwood	Senior Lecturer	2006-present
Period when the claimed impact occurred: Sept 2014 - 31 December 2020		
Is this case study continued from a case study submitted in 2014? No		
<p>1. Summary of the impact</p> <p>Research into the needs of those with problematic drug and alcohol use has informed UK-wide guidance on drug misuse and dependence, and mental health care. It also underpinned a key recommendation in a Government inquiry into human rights and older people. Findings on End of Life care shaped the delivery of Greater Manchester's Drug and Alcohol Strategy and have improved training and cross-agency working nationwide. Endorsed by Public Health England (PHE), Alcohol Research UK, NHS England and Marie Curie, our evidence-based practice guidance has shaped the practice of thousands of health, social care, hospice and homelessness workers in the UK and Canada, benefitting the people they work with and those who care for them.</p>		
<p>2. Underpinning research</p> <p>Galvani, Wright and Yarwood's research responds to a lack of evidence about the complex needs of those with problematic drug and alcohol use, their lived experiences and their interactions with health and social care support services. This case study builds on over GBP750,000 of funded research into social care education and practice, and translational work in this field.</p> <p>Between September 2014 and March 2015, PHE (G1) drew on Galvani's expertise to clarify the role that social workers play when working with alcohol and drug users, to guide workforce development. Exploring the relationship between social work education and practice, and wider systemic and situational constraints, the research filled the gap in existing understanding about social workers' engagement with substance users. Galvani concluded that the social work profession must engage with substance use as part of its core work and education curriculum. The findings culminated in a report, produced with an advisory group comprising senior health and social care personnel, which highlighted three roles that social workers should play: to <i>engage</i> with the topic, to <i>motivate</i> people to consider changing their problematic substance-using behaviour and to support people in their efforts to <i>make and maintain changes</i> [1, 2].</p> <p>Extending a pre-existing relationship, Midlands-based charity, Aquarius, commissioned Galvani to conduct a realist evaluation of its Time of My Life (TOML (G4) project (2015-17) to inform the development of the service and others like it. This brought a spotlight to alcohol use among older people. Working with peer researchers, Galvani found the quality, consistency and support of a person's relationship with their allocated worker was the primary factor that improved their social and health outcomes. She was also able to identify a range of good practice insights into what worked, as it was a wider and more holistic service than the norm for specialist substance-use [3].</p> <p>In 2016, the National Lottery Community Fund awarded Galvani, Yarwood and Wright GBP425,000 (G2) to conduct a ground-breaking two-year research study into the nature and extent of substance problems in palliative and end-of-life care (EoLC), and the experiences of individuals, family members and professionals living and working with these issues. It responded to charities' concerns about whether they were supporting people with substance problems who needed palliative or end-of-life care, as well as they could [4]. Working with two substance-use agencies and three hospices plus community partner, Voicebox, they conducted a Rapid Evidence Assessment, secondary analysis of existing quantitative and qualitative datasets, and four strands of qualitative data collection from people with experience of both issues, family members, professionals and key informants [5]. The project advisory group comprised regional service commissioners, national charities and key people working in this field. There was also an advisory group of people with experience of substance use or palliative and end-of-life care.</p>		

The EoLC research found a dearth of research evidence that identifies effective models of practice for this group of people and a gap in current knowledge about the scale of these overlapping issues. Confirming previous anecdotal reports, it demonstrated that most of this population have complex and multiple difficulties that negatively affect identification, engagement and care. Moreover, the anticipation of discrimination can stop people from presenting to services. Additionally, it warned that services often overlook family members' support needs. As with previous projects, hospice and substance-use professionals identified multiple training and support needs on matters including how to talk about the 'other' issue (end of life) [6]. The findings underpinned a successful NIHR bid (G3) to develop a model of care for people using substances who are at the end of their lives, in partnership with a range of key statutory and non-statutory sector agencies. The model is being developed through participatory action research (PAR), rolled out and tested in Merseyside.

3. References to the research

[1] Galvani, S (2017). Social work and substance use: Ecological perspectives on workforce development, *Drugs: Education, Prevention and Policy*, 24 (6), 469-476, DOI: [10.1080/09687637.2017.1282421](https://doi.org/10.1080/09687637.2017.1282421)

[2] Galvani, S (2015). [Alcohol and other Drug Use: The Roles and Capabilities of Social Workers](#) (report), Manchester Metropolitan University.

[3] Galvani, S, Jeffreys, S, Tan, JP, Albertson, K, Smith, B, Smailes, S and Tanner, D (2017). [Project Evaluation. Time of My Life: an Aquarius service supporting older people?](#) Alcohol Research UK.

[4] Galvani, S, Dance, S and Wright, S (2018). [Research report: Experiences of hospice and substance use professionals: End of Life Care for People with Alcohol and Drug Problems.](#)

[5] Witham, G, Galvani, S, Peacock, M (2019). End of life care for people who use alcohol and other drugs: findings from a Rapid Evidence Assessment, *Health and Social Care in the Community*, 27 (5), 637-650, DOI: [10.1111/hsc.12807](https://doi.org/10.1111/hsc.12807)

[6] Witham, G, Yarwood, G, Wright, S, Galvani, S (2019). An ethical exploration of the narratives surrounding substance use and pain management at the end of life: a discussion paper, *Nursing Ethics*, 27 (5), 1344-1354, DOI: [10.1177/0969733019871685](https://doi.org/10.1177/0969733019871685).

Indicators of Quality

G1 Alcohol and other Drug Use: The Roles and Capabilities of Social Workers, Public Health England, 2015, GBP10,000, PI: Galvani

G2 End of life care and substance use, The Big Lottery Fund, 2016-2018, GBP425,000, PI: Galvani

G3 Will a new model of care for people with end of life care needs who are impacted by problematic substance use improve their access to and experience of support and care? NIHR, 2019-2022, GBP 287,258, PI: Galvani

G4 Evaluation of Aquarius 'Time of My Life' project. Co-funded by Alcohol Research UK and Aquarius. PI, April 2015 - September 2016, GBP55,000, PI: Galvani

- Galvani was appointed to the Advisory Council for the Misuse of Drugs (ACMD) as a result of the body of research in this case study.

4. Details of the impact

People with substance use generally experience multiple, long-term and complex health and social care needs, leaving them particularly vulnerable to exclusion from care services. Although over 265,000 adults were in contact with UK drug and alcohol services last year, most engage only at crisis point. Single-focus policies and solutions also serve this group poorly. Produced with social workers, substance use specialists, NHS workers, and hostel and homelessness professionals across the UK, the team's research generated new knowledge that has helped them to navigate these complex lived realities together. It has improved their confidence, the care they provide and, ultimately, the lives of those with problematic drug and alcohol use, and those who care for them.

Professional guidance: The research has played a critical role in raising awareness of issues surrounding substance use and complex needs at a time when drug and alcohol services are stretched. PHE's Programme Manager for Alcohol and Drug Treatment and Recovery argues the team's research: '*pushed for some priority to continue to be afforded to these important topics despite the challenges, keeping them on the agenda*'. It influenced PHE and Department of Health guidance, including the UK-wide national clinical guidelines on drug misuse and dependence

(2017 - the 'orange book'), which refers clinicians to Galvani's research on the roles and capabilities of social workers. PHE recommends [research-based online resources](#) Galvani and Manchester Met colleagues produced for Health Education North West in its guidance on substance misuse in people with learning disabilities (2016). Galvani also co-produced 'Better care for people with co-occurring mental health and alcohol/drug use conditions' (2017) with PHE, which supports commissioners and service providers with the implementation of the NHS' Five Year Forward View for Mental Health. According to the Programme Manager: *'Through the guidance and their influence on [PHE's] thinking, the research will already have benefited approximately 1,000 services, 200,000 service users, and countless others not in treatment'*. **[A]**

The social work research [1] informed the Advisory Council on the Misuse of Drugs (ACMD)'s 'Vulnerabilities and Substance Use': a briefing the Government commissioned to aid its understanding of the subject in relation to the National Drug Strategy (2017). The ACMD subsequently (2020) appointed Galvani as a member to *'ensure that the Council continues to provide the best possible evidence-based advice on the harms of drug misuse'*. In 2017, Galvani and Wright also contributed to the All Party Parliamentary Group (APPG) for Ageing and Older People's Inquiry into human rights and older people (2018). Their findings underpin Recommendation 3 (the right to healthcare) in the final report, which advocates that: *'We should change how we view dying and provide a more person-centred approach'*. **[B]**

In 2018, Galvani was awarded a MetroPolis Chancellor's Fellowship (see REF5b) to develop the first ever [policy guidelines on End of Life Care](#) (EoLC) for people using substances, in collaboration with Mersey Care NHS Foundation Trust. They refined them through a multi-agency event involving 40 clinicians, commissioners, social care and hostel workers, and launched them in May 2019. They also produced [Good Practice Guidance](#) on EoLC with Marie Curie, Addaction and St John's Hospice, Lancaster, in response to practitioner demand. The Royal College of Psychiatrists (RCP) added a section on 'End of life care issues in older people with substance misuse' to the second edition of 'Our Invisible Addicts,' (2018) citing the EoLC research. The RCP's report forms the focus of its efforts to develop the best possible response to substance misuse in older people **[C]**.

Health and social care: For Aquarius the older people research provided validation: *'Being able to see the difference [the service] makes provides motivation – something that is crucial in drug and alcohol work'*. Time of My Life (TOML)'s managers continually adapted their practice in response to Galvani's insights, keeping them on track to address the project's aims. Her findings on good practice informed the content of a hard-copy pocket guide for health and social workers working with over-50s in Birmingham, co-produced by The British Association of Social Workers (BASW) and distributed to its membership of 15,000. Aquarius also used them to develop a TOML tool and practice guide (2018), which they used to run 150 workshops with 3,070 drug and alcohol commissioners, health workers and care workers. Attendees reported the training opened their eyes, pledged to adapt their own practices, and said they would be more able to help older people with an alcohol problem **[D]**.

Although the TOML service was forced to close when funding ended, the guidance provides *'a practical legacy, which ensures the research's ongoing use'*. Approximately 120 Aquarius practitioners still use the materials, which they say makes them: *'more aware of the needs of older adults using alcohol, how to screen and identify alcohol problems and how to support older adults with alcohol problems'*. This has benefitted the 548 over-55s who use the services every year, and their families. Aquarius was a partner on both EoLC projects: a sustained relationship that has *'helped the charity to distinguish itself from other drug and alcohol services of a similar scale'*. It has also used the research to evidence its innovation and social value in ten successful contract tenders in the past two years, bringing in much-needed funding **[D]**.

The EoLC research has led to further collaboration with social and health care agencies in Liverpool and surrounding areas to develop an improved model for end-of-life care for people using substances. Staff at Marie Curie Hospice, Liverpool, which supports over 1,000 people per year, used the research in a study day in 2018 and continue to share findings with their 74 Healthcare professionals and 200+ volunteers, and in multidisciplinary team (MDT) meetings. The Clinical Director says The Good Practice Guidance has *'been of direct use'* when providing advice, planning treatment, and directing patients, and that the research and collaboration:

has had a clear impact on our staff and our patients and given us more confidence to do our work and do it well. As a result, staff are more aware of the prevalence of alcohol and substance

misuse and are now more willing to ask patients about it. We have also forged links with relevant services and are now able to seek advice readily.

Drawing on examples from her own practice, she describes gaining *'the confidence to support detox from alcohol for a patient in the last weeks of their life'* and enabling one patient *'to establish a positive relationship with their family before their death'*. She also reports that:

The pervading mood has changed. Staff are non-judgemental and confidence has increased....

The changes in our work and the increase in confidence and decrease of anxiety for staff has trickled down to the patients' families too, who seem to have increased trust that we can deliver the care their loved one requires.

Marie Curie (national) was a project partner for both EoLC projects and co-badged the policy standards to demonstrate their commitment to them. Farther afield, the liver team at Sandwell and West Birmingham NHS Trust created an MDT on people with cirrhotic liver disease who are moving into the palliative phase after a consultant used the EoLC materials to start a conversation on the matter [E].

Pendleside Hospice created a substance use and misuse policy (2019) in response to the EoLC research, heavily citing its findings. All Hospice employees and volunteers are required to follow the policy to ensure that care is *'respectful, non-judgmental and safe'*. They have led internal and external training sessions based on the Good Practice Guidance, and invited the researchers to share their findings with 110 staff from 37 organisations at their annual conference. A clinical social worker at Vancouver Coastal Health and Providence Health, Canada who found the Good Practice Guidance online, described it as: *'the only document I have come across that made the leap from research to practice...the kind of guidance that front line care workers are desperately looking for'*. It has informed education sessions attended by *'hundreds of workers'* (representing all interdisciplinary care teams in Vancouver). They find the section on talking about substance use and EoLC, which is a *'significant challenge'* for clinicians, particularly useful. They also incorporated it into a document to guide care-planning conversations with structurally-vulnerable clients [F].

In 2019, A member of the Greater Manchester Health and Social Care Partnership (GMHSCP) shared the EoLC research with drug and alcohol commissioners to address a key action in its draft Drug and Alcohol Strategy. On using it to look at their own services, they found provision was variable across the localities. The commissioners discussed it with their teams, included EoLC in service delivery plans, began to develop firmer care pathways with local hospices, and established End of Life Champions. The work has led to an acknowledgement that *'drug and alcohol services have a part to play in ensuring that end of life care is appropriate, meets the needs of the individual and that those conversations happen'*. Wright and GMHSCP's End of Life team also led a training day where the Champions developed and agreed an EoLC pathway, cascading learning to colleagues. This embedded EoLC in the Partnership's work:

End of Life care hadn't previously been identified as a priority as part of the Drug and Alcohol Strategy but it now is...the fact that the seven Champions and the pathway are now in place across Greater Manchester is a key benefit. There is a cohort of staff across the system who have an understanding of End of Life care that will impact on all members of the drug and alcohol community that are engaging with us. [G]

Homelessness services: The Homeless Service Lead for St Luke's Hospice, Cheshire, was invited to join the EoLC advisory group in 2015 when the service was in development. The research provided evidence that backed up what the Lead saw in practice, for example, that pain management was an issue. She says: *'this gave me the courage to fight harder for the patient as I could see this was not local to just my area'*. Now, when someone using drugs is in pain, they call a multi-disciplinary professionals' meeting *'prescribing in a way which is both safe for the patient and the professionals'*. The research also confirmed her observations about family suffering, strengthening her existing desire to support them, and shaping the service. The hospice website now profiles 'Daley's story' - a case study based on a mother's experience of the dignified care they provided for her son, who used substances. The mother asserts: *'Daley was very privileged to die at St Luke's. He knew that. He couldn't have got anything better'*. [H]

The Palliative Care Coordinator for London-based homelessness charity, St. Mungo's, incorporated the EoLC research into training for 250 staff across front-line services (2018-2020), with a particular focus on the findings and guidance around communication skills. Her evaluation showed a 90% increase in confidence amongst attendees. They reported feeling better equipped

to deal with palliative care issues, more knowledgeable about services available to support them and said they had adapted their practice as a result. Wright also provided guidance and advice around their data on homeless deaths, supporting analysis that informed further training and education [I].

Staff at Marie Curie Liverpool use the EoLC research in collaboration with a local GP practice. In 2019, one of the hospice's consultants developed a system to support people who are homeless, utilising the Gold Standards Framework. The practice now holds meetings for homeless patients, which hospice staff regularly attend, providing palliative care input for people with substance misuse issues. When needed, the consultant accompanies a GP or community nurse to review people in their current place of residence (e.g. a hostel). They draw on the research insights into the design of collaborative services and supporting people with multiple complexities, *'in particular the fears that people with a past substance misuse history have regarding use of opiates'*. The research informed a successful grant application for a 'Homelessness and Palliative Care Coordinator' who started work in 2020. They have also used the Good Practice Guidance to upskill the team at the Royal Liverpool University Hospital as part of monthly multidisciplinary meetings set up for patients with end-stage liver disease. They draw on the section that focuses on experiences of family, friends and carers, to ensure that their needs are included in service specifications [E].

In 2019, the cross-agency Drug and Alcohol Action Team in Truro, Cornwall, invited our researchers to run several EoLC workshops to enhance its CPD programme. They report that the policy standards and good practice guidance *'have given [them] standards to begin to work towards, a research base to support changes in practice and examples of good practice to learn from'*. The research underpinned a successful grant for a project worker who is now taking forward joint work between hospice, community health and housing teams [J]. St Ann's Hospice, Manchester, also invited Wright to be on the induction team for its new Homeless Palliative Care Coordinator role in January 2020. The team's guidance was *'pivotal'* in providing insights into key considerations when setting up a service. The Coordinator has integrated the EoLC research into her training for homeless sector staff, finding insights, guidance and advice around communication *'particularly useful for healthcare staff in terms of setting out the things that are important to consider when approaching patients who might have substance use issues'*. The project has also informed advance care planning with clients, helping her to address their wishes. She says: *'the findings and resources from the research have changed my practice with regard to how I approach them but also in how I support better multi-disciplinary working'*. [H]

5. Sources to corroborate the impact

[A] i Testimonial, Programme Manager, Alcohol and Drug Treatment and Recovery, PHE; ii Department of Health, ['Drug misuse and dependence: UK guidelines on clinical management,'](#) 2017; iii PHE, ['Substance misuse in people with learning disabilities: reasonable adjustments guidance,'](#) 2016; iv ['Better care for people with co-occurring mental health and alcohol/drug use conditions. A guide for commissioners and service providers,'](#) 2017.

[B] i Advisory Council on the Misuse of Drugs, ['Report on Vulnerabilities and Substance Use,'](#) 2018; ii Notice of appointment to ACMD; iii APPG Ageing and Older People, ['Inquiry into human rights and older people: Protecting our rights as we age,'](#) 2018.

[C] i ['Policy standards: a working document,'](#) 2019; ii ['Good Practice Guidance,'](#) 2019; iii Royal College of Psychiatrists, ['Our invisible addicts'](#) (College Report CR211), 2018.

[D] i Testimonial, Chief Executive Officer, Aquarius; ii Guide: Alcohol and older people, 2018.

[E] Testimonial, Clinical Director, Marie Curie Hospice, Liverpool.

[F] i Pendleside Hospice, Substance Use and Misuse policy, 2019; ii Testimonial, Palliative Medicine Consultant, Sandwell and Birmingham NHS Trust; iii Testimonial, Leader Regional Palliative Approach to Care, Vancouver Coastal Health and Providence Health Care, Canada.

[G] Testimonial, Greater Manchester Health and Social Care Partnership.

[H] Testimonial, Homelessness Project Coordinator, St Luke's Hospice, Cheshire.

[I] Testimonial, former Palliative Care Coordinator, St Mungo's, now Homeless Palliative Care Coordinator, St Ann's Hospice.

[J] i Testimonial, Consultant in Palliative Medicine, Cornwall Hospice Care and Senior Primary Care Development Manager, Communities Service, Cornwall Council; ii Advertisement and role profile, Improving Access Project Coordinator, St Austell Healthcare.