

# Saving Lives With GPS

## Summary

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### SCANNING

High Risk Missing persons are a resource intensive and exponentially increasing area of work for UK policing. Within this group sits a cohort that is particularly hard to find. They are at an increased risk of serious harm and death. These are people living with dementia who are at risk of “wandering.” The harm is not limited to the person, the stresses, pressures, and cost placed on carers, emergency services, health, and social care, are vast.

### ANALYSIS

Dementia is a brain disease that affects cognition and memory. There is no cure. Police cannot affect the underlying condition. Locking people in their own home is unethical and unsafe. Fulltime care is expensive or impractical. Institutionalisation leads to premature death. Technology is sufficiently well advanced to mitigate the cognitive deficit and support capable guardianship of the person living with dementia. There are ethical, legal and practical barriers to tracking a person to enable capable guardianship.

### RESPONSE

One highly motivated, driven, and persistent individual formulated a plan using his years of police search experience. Whilst seeking legal counsel and ethical oversight he obtained funding to trial GPS technology to allow the carer to track their loved one living with dementia should they go wandering. A cohort of fifty people living with dementia were identified and provided with a tracker. Their families were taught how to use the technology as police were deliberately excluded from accessing the data to overcome the legal and ethical barriers. Following initial assessment this methodology was adapted to provide a fully upstream deployment model that could be replicated at scale.

### ASSESSMENT

The initial cohort who had dementia and had previously been high-risk missing people. Twelve months before the trial there were eighty-four missing episodes from this group. All of these were graded as High Risk. During the twelve months of the trial, there was just one missing episode. Any wandering that did take place was quickly and efficiently resolved by the families. Having established efficacy, the trackers were deployed at point of diagnosis leading to the virtual elimination of the problem of high-risk missing from home with dementia as a cause. This was supported by a control comparison where the trackers were not deployed in this way.

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## Scanning – Phase 1

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In 2022/23, missing person (MP) episodes in England and Wales were reported at 312,901. This equates to someone being reported missing every 90 seconds in the UK. The average cost to the police service of a medium-risk missing person is £2,415.80. This rises to £8,800 for the first hour of high-risk missing persons (HRMP). Recent NCA statistics show that the number of fatal outcomes has been increasing year-on-year since 2016-17. In 2022/23, there were 955 fatal outcomes in the UK, compared to 711 in 2016-17: a 34% increase. The vast majority (97%) of these cases relate to missing adults: 926 missing adult episodes resulted in a fatal outcome in 2019-20. This demonstrates that this is an exponentially increasing problem.

Dementia is a disability which can significantly affect patients' cognition and navigation. It is estimated that 40% of people diagnosed with dementia will get lost, with 5%-27% of these acutely vulnerable people getting lost repeatedly. When patients get lost, this causes significant emotional distress, both to the person living with dementia and to their family and carers. In the worst case this can result in physical harm or death. This is also associated with overwhelming distress and anxiety for family members who are trying to support their loved one. This increasing problem has an enormous impact on the emergency services, the health and social care sector, as well as society at large.

There are currently around one million people living with dementia in the UK. As the population grows and ages, this will exceed 1.5 million by 2050. This chart shows the upward trajectory of people suffering with dementia in the UK:

Wandering behavior often results in people being institutionalized, limiting a person's freedom, potentially resulting in a reduction in both mental and physical health and at a significant cost. These patients seek help through a variety of services including their primary care practitioner, mental health services, police, ambulance service or health emergency departments. This may represent multiple clinical appointments and input from primary care specialists. These patients are subsequently referred to specialist secondary care clinicians through specialist memory services, where they are seen by trained specialists. This can be a protracted and complex process to both primary and secondary care services. From a safeguarding perspective, wandering behavior can lead to significant harm and death if person who is lost is not found as soon as possible, and there have been a series of serious incidents across South Yorkshire in recent years.

Once the person has been returned to their loved one there is the stress that the thought of further episodes causes. The most used solution is for the person's family to suspend their normal life and valiantly try to care for their partner or parent for 24 hours a day, 7 days a week. Which will continue until crisis point is met, when the patient will move into a care setting. The average cost of placing a person in a care home in the UK is now £1,266 per week. For nursing homes, the cost rises to £1,529 per week. Currently if the person has more than £23,000 in savings or own their own home then care must be paid for by the individual. If not, then the local council will have to pay.

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To illustrate this further, Rotherham Metropolitan Borough Council's (RMBC) maximum weekly contribution is £793, excluding the funded nursing care (FNC) of £235.88 per week, bringing the total cost to RMBC to £1,028.88 per person per week in a nursing home with dementia. As of March 2023, there were 2,631 people registered in Rotherham with dementia. The real number is expected to be 3,128. Between 30-40% of people with dementia live in care/nursing homes. This is approximately 1,000 people in Rotherham alone, costing £1,028,880 per week.

Barnsley Metropolitan Borough Council (BMBC) published figures Oct 2023, median costs per week for care home without nursing with Dementia £742.09 per week. Care home with nursing with Dementia £1069.70. BMBC funding for the year 22/23 £25.384m on residential and nursing care.

## Analysis – Phase 1

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Dementia is a brain disease with multiple causes and no cure or long-term treatment. We understand that this disease is the underlying cause of the missing episodes. The disease or its symptoms is not something that we as police officers can affect, even with the help of partners. We therefore need to identify what we can change.

Use of routine activity theory and the problem analysis triangle quickly identifies the person living with dementia as the focus of any action.

Changes to the residence of the person living with dementia, could be considered. This can be excessively punitive when considering the restriction on the liberty of the individual. The deprivation of liberty, the locking in of the person with dementia into their own home could not be recommended ethically, or safely as a solution by police. Institutionalisation, as an alternative to locking in, is proven to reduce the life expectancy and quality of life of the person living with dementia. Exercise and social contact have been proven to delay the onset and escalation of the disease.

The sacrifices of carers to look after their loved one are huge. Sadly, this is not always enough to prevent the missing episodes, as carers have jobs and lives to fit around their caring responsibilities. The carer may even have vulnerabilities of their own. The lack of capable guardianship is rarely due to lack of effort. A solution should seek to amplify the carers capability whilst reducing the effort and mental load. Fulltime, or paid, supervision could also be considered excessive with the sporadic nature of the missing episodes.

The person living with dementia is not carrying out a premeditated action. There is no underlying desire or need to be found. The person goes missing because of their deficit of cognition, memory, and executive function. A solution or protective practices that mitigates this deficit has the potential to prevent harm coming to the sufferer, whilst enabling them to remain in the own home for longer. The affect of this would be to reduce the risk to the sufferer, reduce the stress on the family and reduce the resources needed from the public sector.

Focusing on the deficit in cognition and memory, allows for the application of a straightforward technological solution to mitigate the deficit. This is the opportunity to affect change. The lack of intent means that the subject is not likely to take any action to conceal their whereabouts nor discard a technical device.

Following the thorough analysis of the problem, this pinch point was identified. By empowering of a capable guardian, this pinch point could be mitigated or removed.

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A lot could be learned from review existing interventions. Examples of these are the Hebert Protocol, Operation Magnet in Hampshire, and Avon and Somerset's initiative to use "Buddy" trackers to locate people.

The Herbert Protocol relies heavily on an investigative response by police once the person living with dementia is already missing, by identifying significant places in the person living with dementia's past or present that might result in the early resolution of a missing episode. This practice, although valuable, fails to address the problem far enough upstream to have transformative benefits that we sought.

The use of third-party monitoring as in the Hampshire and Avon and Somerset trials have their own short comings. Buddy tags rely on second generation mobile phone technology and do not provide an accurate fix on the missing person's location. The most successful of these programs was Op Magnet, which, with the use of GPS pendants was able to reduce missing episodes reported to the police by 65%. These programs still rely on police intervention and third-party monitoring companies. This not only infringes privacy and human rights but also consumes resources.

What was required was a simple, accurate, private, and legal solution with genuine upstream demand reduction capability.

There were significant obstacles to overcome to implement a viable solution. It was quickly established that the technology in GPS tracking was sufficiently well advanced to be able to utilize a device that was low cost, small, reliable, and easy to use. The device needed to be easy to use in terms of both the deployment on a person and for the capable guardian to be able to use the software on a suitable device and be able to find their charge in a timely fashion.

Police Constable John Porter, the Search Lead for South Yorkshire, who had led searches for numerous missing people, including a life critical three-day operation to find someone with dementia who went missing, took it upon himself to overcome the significant barriers presented. He was told his idea would not work. He was told it would be unlawful. He was told it was unethical. He was told the technology would fail. But he recognized that if these barriers could be navigated, it would be life-changing for the people involved. It would create huge savings across the public sector.

Hypotheses:

1. GPS trackers will decrease the incidence of harm from wandering for people diagnosed with dementia or memory impairment.
2. Wearing a GPS tracker will reduce the use of the police to help locate the individuals.
3. Wearing a GPS tracker will improve the quality of life of both the individual and their carers.
4. People diagnosed with dementia or memory impairment, and their carers will find GPS trackers useable and acceptable.
5. The legal, ethical, and technological barriers are too significant to make this solution possible and cost affective.

## Response – Phase 1

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The first hurdle to overcome was the funding. The potential savings from the project were massive. These represented downstream savings, operation costs rather than cashable savings. The use of technology necessitated an upfront cost. The project required investment to get off the ground.

From the outset, there was an awareness of the significant ethical, legal, and technological challenges to overcome. Overcoming these barriers would be pointless without funding. A plan was proposed to address these significant barriers, which suggested that a viable methodology could be achieved. The force's Innovation Fund awarded £10,000 to develop the solution.

With funding in place, and a plan to overcome the legal, ethical, and technological obstacles, the real work could begin.

The identification of the correct technology was intrinsic to the success of the project. The tracker needed to function with sufficient ease and provide clear data to the user, i.e., capable family member. The tracker also needed to be sufficiently unobtrusive to be easily worn by the person living with dementia.

A tracker that could be work as either a pendant necklace or as an attachment to the belt was identified. With ease of wearing and engagement with the habitual behavior of the person living with dementia, the chances of successful tracking were established. Two alternatives were identified, each unit costing around £200 with on-costs.

The next challenge was to address data privacy concerns to ensure that information sharing was lawful, to the satisfaction of force experts. This sign-off involved a lengthy application process through the Data Protection Team. Despite the sign off taking 3 months, the final design of the trial affectively negates the data privacy concerns entirely.

People living with dementia who were at risk of wandering were identified and would be offered the opportunity to participate in the trial. GPS trackers and supporting software were purchased by South Yorkshire Police (SYP) and were gifted to the person diagnosed with dementia, to be monitored by their family. This efficiently sidesteps the issues of the police collating location data and other data privacy considerations.

The ethical and legal considerations needed to be overcome next. The project was presented to the internal ethics committee. This helped to tease out all the ethical and legal implications of the project.

An independent human rights barrister was engaged to advise upon these issues, that are underpinned by international human rights law. There was a clear infringement of the article 8, Right to Privacy, however this could under the circumstance be superseded by article 2, Right to Life. The advice was given that providing the next of kin was the person tracking or they had power of attorney over the wearer, it would be legal and proportionate to track their movements to save life. This advice resulted in support from the internal ethics panel and internal legal services.

A responsible and capable person has control of the location data on a smart device. This provides a "breadcrumb" trail following the missing person and will also retain their movement history, should contact with the device be lost.

## Saving Lives With GPS

A cohort of 50 people living with dementia who had previous missing episodes were identified through the manual extraction of data from the missing person system. Their previous episodes could then be costed. This gave baseline data for comparison.

The identification of a trial cohort was spread across force and included males and females living with dementia. The trial was designed for fifty participants and was to be free of charge for the duration of the trial. Participation was voluntary and they could withdraw at any time. The participants must reside in the community and have a person with power of attorney responsible for their care. Finally, and most importantly, the participant must have a diagnosis of dementia. The potential cohort were identified from the missing person systems, meaning they has a history of wandering. The families were then contacted to identify that a suitable support network was in place and then to seek willingness to participate.

The carers were provided with training on how to use the trackers and the software and were given a simple flow-chart (figure 1) to follow. The participants and their carers were asked to provide feedback through a simple survey as another means of capturing the benefits.

Figure 1 Flow chart provided to carers to assist with decision making.

## Assessment – Phase 1

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In the year before the trial, across the South Yorkshire area, the fifty people from the cohort, went missing eighty-four times. This totalled 397 missing hours. Based on each investigation costing £10,700 the total cost to the force of £898,800. This is without the deployment of a helicopter, this costs £3,200 per hours of deployment.

The trial lasted for twelve months. Fifty trackers were given to families. During the twelve-month trial, there was only one missing episode related to dementia from this group. This missing episode lasted for seven hours and would have cost the force £10,700.

This represents an incredible 98% reduction in time lost and a 99% reduction in missing episodes.

This is a cost saving to the force of 99% compared with the previous year.

Pre-trial, of the eighty-four missing episodes, forty-six of those required an ambulance to provide a medical intervention costing £19,274 for the attendance of an ambulance alone.

During the trial, the number of medical interventions required were zero having a 100% saving for the NHS.

For the investment of £10,000 the savings post-trial were £889,100. This equates to a 99% reduction in costs.

A qualitative assessment of the trial obtained feedback from the families of the users. This showed that there were forty occasions where the wearer wandered, and the families used the GPS tracker app to locate the wearer and calmly return them to safety without any need for police intervention.

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It is therefore reasonable to infer that the work carried out with the families to identify the risk to their loved one has a preventative affect that stops the missing episodes from occurring in the first place. The mechanism of this could be through greater awareness of the risks or through the identification of risky behavior prior to an episode taking place.

The reductions in demands and costs are important. But this is about people. This is about reducing the risk to the person who goes missing and the harm to their family, who must live on edge, waiting for their loved one to walk off and their life to be put at risk again. Families talk about their exhaustion and feelings of desperation.

One family that participated in the study were able to take their father on holiday with them to a static caravan, something which they had not been able to do since his first missing episode. Whilst in bed, the daughter's mobile 'phone alerted them to the GPS tracker leaving its geo-fence (the Caravan). They found their dad in his pyjamas walking between caravans within the complex. This was less than 15 minutes after him leaving their caravan. The site had seven lakes as part of the complex and without the tracker there was a real possibility that their father could have drowned, the family would only have discovered his absence on waking in the morning.

One user from Doncaster who has early onset dementia wears the tracker and is now able to go for a walk as his wife can watch where he goes. She tells him to walk for a coffee and she will meet him there. She sets off five minutes after him and by watching the tracker on the app live time can pick him up when he makes a wrong turn. This is an example of the GPS unit being used preventatively, enabling the couple to have some normality with a safety net around him.

## Scanning – Phase 2

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Following the conclusion of the initial trial with a cohort of 50 persons there was a proof of concept for the project. The data showed the value of the intervention for the identified cohort. This presenting significant savings for the force regarding the cohort. This was not reflected in the force wide data with no significant reduction in missing episodes relating to dementia. It was clear from the data that the impact force wide was not as significant as it had the potential to be.

	Barnsley	Doncaster	Rotherham	Sheffield
2020	20	43	22	58
2021	28	37	28	47

## Analysis – Phase 2

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The data from the trial cohort showed the positive impact that the trackers have on the individual and on the cohort population. The trial proved the concept of the tracking and the use of them as a response. The result from the cohort after intervention showed the value of the methodology. The new identified pinch point was the early identification of users and carers.

## Saving Lives With GPS

The model used to identify the trial cohort is reliant on the person living with dementia having already been a high-risk missing person. This necessarily means that the risk, and the cost, has occurred at least once. Following this model there would always be an incomplete picture of people living in the population at risk of wandering. What was needed was a better way of identifying the risk, and earlier intervention that was as far upstream of the problem as practicable.

It was clear that this solution would be beyond the remit of police working in isolation. The skills needed for the early identification of risk sat with Health Care professionals. Whilst the benefits to law enforcement were clear, the reduction in demand did not represent significant cashable savings, such that police budgets would support the large-scale deployment to realize the full benefits of the trackers. If the hypothesis that the trackers delayed the need for residential care was proved true, then the most significant short-term beneficiary would be Adult Social Care. In the UK, adult social care is funded by the local authorities through a combination of local taxation and central government grant.

This analysis demonstrated the need for a multiagency, multidisciplinary response.

### Hypothesise Phase 2

1. Health Care has the best opportunity to identify those at risk of wandering.
2. Social Care will be the primary beneficiary in cashable savings.
3. The qualitative benefits from the trackers for the subjects and their families will be significant.

## Response – Phase 2

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During the initial trial, John had been in contact with a health care academic from Huddersfield University, Professor Doyle. This was to take advice on the efficacy of the trial. Prof. Doyle became interested in running a similar program. Once the SYP trial demonstrated proof of concept, John worked with Professor Doyle to complete a similar study using different methodology. Where the initial trial wanted to reduce risk to the person living with dementia and demand on police and partner resource, the new study was looking at the wider implications to the family, employers, and care providers of those living with dementia. This unlikely partnership, between an academic and operational police officer has proven to be invaluable developing a new model for the identification of risk and deployment of the solution.

Funding was again key. Through his contacts at Barnsley Council, John persuaded them to fund the second study. This was leveraged through the proposition that the Council would be the immediate beneficiary through reduced adult social care demand. £100,000 funded the trackers, and crucially two researchers from the university, to carry out the deployment and training for use of the trackers.

Instead of waiting for someone to be a high-risk missing person, through his health care contacts, Prof. Doyle was able to have the trackers deployed at the point of diagnosis through the memory clinics. This ensured the capture of every person in Barnsley with a dementia diagnosis, they were then offered a tracker. This was the key change that would unlock the upstream problem-solving the initial trial had teased. This became the Barnsley Prescribing Model (BPM).

## Assessment – Phase 2

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To understand the comparative data following the deployment of BPM it is necessary to understand the boundaries of the SYP area. SYP is divided into four metropolitan borough councils (MBC), that provide services to the residents. Sheffield is the largest with a population of 757,000, Doncaster 308,700, Rotherham 265,000 and Barnsley 248,000. Social care is devolved to the MBCs, Health Care follows similar structure, policing is county wide.

The BPM data shows stark differences in the number of people going missing across the county, with dementia as the cause. This is further illustrated when you examine the detail of the missing episodes in Barnsley. In 2024 four people, all wearing trackers went missing. The carers were unable to get to them in a timely manner and contacted police, talking them into the exact location and recovering their loved one within the hour. No medical intervention was required. There was no trauma to the person living with dementia. No distress for the families.

The BPM trial results mimic those of the SYP trial, only with huge amplification. There is also strong evidence of significant wider positive impact that it was not possible to measure in the initial trial.

“Wearers and carers had a greater sense of safety, were better connected should help be required, and participants were willing to continue using the trackers at their own expense. The confidence, ‘peace of mind’, and the ability to locate the person with dementia quickly and safely with less need to involve the police support the conclusion that the technology can potentially delay admission into a 24-hours care setting.”

Carers confirmed that the GPS intervention delayed the move to residential care. We can’t say by how long or for how many there would be a delay in move to residential care, but a simple cost-benefit analysis would suggest that the first-year cost for the GPS intervention per day of £445 would be covered if a move to a nursing home was delayed by 2.75 days, assuming daily cost of nursing home care of £161 (£1125 per week). Put another way, one person staying out of nursing home for one year would pay for 70% (£58500) of the total costs of issuing 180 trackers, and one other person staying out for five months would cover the rest of the GPS intervention costs.

## Saving Lives With GPS

There has been interest at a national level for the deployment of this methodology. Now that this concept has been proven there is a desire to implement the use of trackers at the point of diagnosis across the country. On referral to the memory clinic the tracker will be supplied by the health care professional, and the family taught how to use it. This is truly upstream demand reduction. With implementation at this point it would mean that the police would be unlikely to ever have to find another person with a dementia diagnosis, and this could be rolled out at scale, for minimal cost, resulting massively in reduced risks to life and in huge saving for Health, Social Care and Emergency Services. The project has been described by the Office of the Police Chief Scientific Advisor as “the number one productivity multiplier to be upscaled nationally.”

This project has shown that the tenacity of one officer, using cheap technology can have a profoundly positive impact on the lives of the people living with dementia and their families. This work has saved lives. This work has prevented suffering in the families of those living with dementia. It has saved money and resources of an already overstretch public sector. With the right support this can become a nationwide solution.

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