

## Using telemonitoring to support personal care planning for adults with learning disabilities

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<Title page>

## **Using tele-monitoring to support personal care planning for adults with learning disabilities**

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## **Abstract**

**Introduction:** We report on an evaluation of the Just Right (JR) approach for planning care for adults with learning disabilities (AWLD) and how it can support culture change. JR combines installing a tele-monitoring system with training for care managers in person centred care planning (PCP) and the interpretation of charts that summarise activity data for their setting. By providing insights into the needs of individuals JR allows existing care provision to be reviewed to ensure it is 'just right'. The JR approach can also potentially identify over-care and resources that can be released.

**Methods:** A mixed method approach was used, triangulating qualitative and quantitative baseline and follow-up data. Qualitative data were collected before and after implementation through focus groups on barriers, enablers, success outcomes and impacts. A theory of change was developed. Detailed data on individual AWLDs were collected before and after installation of equipment using a linked online survey completed by their care managers.

**Results:** Nine commissioning local authorities were recruited with 33 care providers serving 417 AWLD. Issues relating to implementation included staff acceptance, culture, consent, safeguarding, local authority engagement, interpretation of data and setting. Changes to care were identified for 20.3% of individuals with 66% of providers not identifying any changes because JR confirmed they were providing the right level of support.

**Discussion:** By combining telemonitoring and PCP, JR provides a holistic approach and necessary information for conversations amongst stakeholders about the care needs of AWLDs. Depending on how

it is introduced, and the nature of conversations held, JR approach can potentially change culture leading to improved outcomes.

**Keywords:** adults with learning disabilities, tele-monitoring, telecare, person centred care, evaluation, cost saving

## **Introduction**

It was estimated that in England in 2015 there were 23,075 adults with learning disabilities (AWLD) residing in supported accommodation, 12,425 in local authority tenancies, housing associations or registered social landlords and 1,195 in sheltered housing. Expenditure on social care for working age AWLD was estimated to be £5.38 billion in 2013-14<sup>1</sup>.

A survey of Directors of Adult Social Services reported AWLD could benefit from increased use of technology with more evidence on best use in providing care<sup>2</sup>. There are small scale pilots (local initiatives) on using telecare for AWLD showing how care can be reconfigured, choice increased to users and families, potential savings and improved planning and sustainability of services<sup>3-7</sup>, but few provide the information required for developing guidelines or commissioners and providers in planning care. In England, the National Institute for Health and Care Excellence (NICE) has produced guidelines covering the identification, assessment and regular reviews of care and support needs of AWLD, the provision of information, advice, training and support for AWLD and their carers; and care and support planning and crisis and risk management<sup>8-12</sup>.

The Just Right (JR) approach represents innovative use of telemonitoring in the planning of care for AWLDs which is dependent on a change in culture amongst commissioners and providers of care. The wider literature on telehealth, telecoaching and telecare has focused on the management of chronic conditions such as chronic heart failure<sup>13</sup>, chronic obstructive pulmonary disease (COPD)<sup>14</sup> or enabling frail elderly to continue living in their homes<sup>15,16</sup>. Whereas the *'evidence base for with learning disability in contrast, relatively scant.'*<sup>17</sup> The literature relating to telecare of AWLDs describes the use of assistive technology to support greater independence or monitoring for safeguarding purposes<sup>18</sup> or explores the ethical issues around the use of technology with AWLDs<sup>19</sup>.

#### *The Just Right approach*

JR combines using movement sensors to provide data presented graphically about the activity of AWLD within their homes over a period of at least six weeks alongside training and advice about person centred care planning. JR uses the Just Checking (JC) system (Just Checking Ltd, Lapworth, England) originally developed for adults with dementia and involves placing motion and other sensors in the homes of AWLD and transmission of continuous monitoring data to a central secure server. Its distinctive feature is proprietary web based software that combines data collected from sensors in a given setting and visually presenting it as a chart to aide interpretation by care managers and other health and social care professionals. Technical support and assistance in interpreting charts is provided by a customer support team. Training was provided in interpreting charts, the principles of person centred care (PCC) and using charts in reviewing packages of care (e.g. if chart shows a AWLD receiving care from waking night staff consistently sleeps through the night then less expensive sleep over staff or removing staff at night entirely may be considered).

Innovate UK's Small Business Research Initiative grant scheme administered by SBIR Healthcare funded a large scale pilot of JR. This pilot provided information against the five sets of determinants in Broens and colleagues layered implementation model of telecare: technology (support, training, usability, quality), acceptance (attitudes, evidence based, diffusion and dissemination), financing (provider, structure), organization (within, collaborations) and policy (policies, standardization, security)<sup>20</sup>.

#### *Potential to support culture change*

Our evaluation was concerned with the potential for change in culture in the commissioning and delivery of care for AWLD, based on conversations that occur from using JR approach in planning and delivering care at a *macro* (how commissioning authorities work with providers and other institutions), *meso* (how providers work with staff, health and social care providers and other stakeholders) and *micro* (the co-creation and delivery of care packages for individual AWLDs) level and how these might be represented in a theory of change<sup>21</sup>. Ford and Ford argue that communication is more than a tool in the change process; but rather change is a phenomenon that results from communication<sup>22, 23</sup>. There are four types of conversations that stakeholders must have for intentional changes to occur and '*that each type of conversation plays a distinctly different role in advancing the change process*' (p.572-3, <sup>23</sup>). The first type is '*initiative conversations*' that start change by focusing on what could, or should be, done. An example, in this case would be the pitch to commissioning authorities and service providers on why they should adopt the JR approach. The second type is concerned with generating shared understanding about the situation, cause-effect relationships, the problem and opportunity and how to move forward. They help specify the '*conditions of satisfaction*' for change, the end point and required '*degree of involvement, participation and support*' of stakeholders. Without these conversations stakeholders may be resistant to change as they do not understand what is planned and their role. The third type involves

*'conversations for performance'* where the focus is producing the intended results and the final type involves signalling closure of the change project. The JR approach required all four types of conversations and the pilot was designed to facilitate them. Workshops were held with staffs from commissioners and providers in each participating local authority area at the beginning for initiative conversations around the need for change and to develop a shared theory of what successful change would look like and towards the end to discuss performance and closure of the pilot.

## **Methods**

A mixed method approach was used triangulating qualitative and quantitative baseline and follow-up data collected through approaches summarised below.

### *Technology*

The Just Checking system (Just Checking Ltd, Lapworth, United Kingdom) was originally developed to support older people with dementia to continue to live independently in their own homes. It comprises of a central plug-in hub with a mobile SIM removing the need for an internet connection and the placement of sensors on doors and movement sensors with the residents' consent. Velcro strips are used to attach sensors so that they can easily be relocated or removed if they cause distress. The system has CE and Australian tick marks and provides continuous 24/7 monitoring and transmission of monitoring data to a central secure server<sup>24</sup>.

### *Qualitative baseline and development of theory of change*

Focus groups were led by members of the evaluation team and were held at 'Go live' workshops organised by the JC project manager with the lead official in each of nine participating local authorities

(LAs). These workshops built on previous 'initiative conversations' that JC had had with the LA and LA with their care providers and provided an opportunity for 'conversations of understanding' around the aims of the JR and how these translated into the specific contexts of LAs and their providers. Workshops were attended by members of the commissioning authority (lead official, contract managers and social workers) and representatives of providers that had agreed to take part in the pilot (care managers and care staff who were able to attend). The workshops were not attended by other stakeholders. As workshops included training in the use of the technology, the focus group took place early in the day to avoid group members' responses being influenced. Discussions formed the basis of a qualitative baseline that included: motivations for being involved, expectations around the technology, anticipated outcomes, concerns and potential barriers. The focus groups were audio recorded with the consent of the group members. The client independently commissioned an illustrator to capture wider discussions within the workshop. The information collected was analysed and used to develop a supporting theory of change<sup>21</sup> for this evaluation (Figure 1).

**INSERT FIGURE 1 ABOUT HERE (Theory of change)**

#### *Qualitative follow-up*

In accordance with the original study protocol agreed with JC, the first follow up focus group was piloted six weeks after the installation of JC equipment. It was clear that the six week period was not sufficient to capture any change so the follow up period was extended to a minimum of three months. The final format included a presentation of the qualitative baseline so participants were familiar with issues identified in other LAs. These focus groups were undertaken by the evaluation team and provided an opportunity for conversations around performance of JR at macro-, meso- and micro-level and for closure. Areas explored included changing culture and attitudes, using JC system and the ability to re-



allocate resources. Participants were also asked to identify the biggest successes, enablers and challenges to implementing JR and areas for future development. While the focus groups shared a common structure, issues covered varied because of the experiences of the members and the particular local authority contexts in which they were operating. For these reasons it is not possible to quantify the prevalence of themes.

#### *Quantitative baseline and follow-up: surveys completed by provider sites*

Detailed information was collected on individual AWLDs at baseline and follow-up using an online questionnaire to provide information on change at the micro level. These were completed by providers for each residential setting by the responsible care manager. Data were collected on the setting (capacity, number of residents, local authority, core hours) and individuals (care needs, care package, personal care plan, important goals, use of assistive technology). In the follow-up survey care managers reported for each resident how information provided by JC system had influenced their assessment of needs, resulted in potential changes to PCPs being identified and whether these were being implemented and the factors influencing implementation. For the individuals for whom they did not identify potential changes, they were able to select from a range of pre-defined reasons.

A condition of the University of Birmingham Ethics Committee approval was that the evaluation used anonymised data. Steps taken to ensure anonymity are described in supplementary material.

#### *Analysis of the data*

A thematic analysis of the focus groups and open questions in the online surveys was performed using a framework analysis approach<sup>25</sup>. Survey data were analysed using SPSS for Windows Version 22.

## **Results**

### **Pilot participants**

Just Right was rolled out in nine LAs (3 large urban metropolitan authorities, 1 London Borough and 5 county councils) over the period July 2014 to June 2016 and included 33 different providers (covering the spectrum from small local third sector specialist providers of residential care to large housing association that provided more independent living units and local authority accommodation) and 170 sites. Because of the need to maintain anonymity of AWLD we limited the information we collected. Survey data were collected from 166 sites on 417 tenants at baseline and 380 at follow-up. The response rate was 97 per cent with a respectable follow up rate of 91 per cent (of tenants) (Table 1). Sites ranged in type and capacity from single person independent living accommodation often in blocks to multi-person residential homes. Most tenants lived in supported living accommodation (83.9%) under a shared tenancy agreement with their care provider (57.8%) (Table 2).

**INSERT TABLE 1 ABOUT HERE**

**INSERT TABLE 2 ABOUT HERE**

The most common care needs identified were personal safety and harm (66%), anxiety and distress (66%) and requires personal care and physical support (63%) (Figure 2).

**INSERT FIGURE 2 ABOUT HERE**

The survey did not collect information on age and gender of AWLDs residing in participating sites.

## **Implementation of Just Right**

The survey and follow up focus groups confirmed many of the anticipated challenges in implementing JR identified at baseline focus group (see Supplementary Information).

### *Acceptance of JR*

Initially care staffs were uncomfortable with the introduction of JR across all 9 participating LAs. They were suspicious and fearful of the technology and did not wish to engage as they perceived JR as a threat to their job security as result of potential changes to staffing requirements (Focus groups in LA1-5). Acceptance by staff was reduced where managers explicitly used information generated for performance management purposes ('checking up on staff') (care provider staff, LA1).

Individuals with autism were less accepting and would remove, or switch off, equipment (care managers, LA5, 7). Care managers emphasised quickly that they responding to tenants' concerns by removing sensors from a tenants' room if they were stressed by their presence (care providers, LA1).

Families were also anxious about assistive technology potentially replacing waking night staff. Providers referred to *'biggest challenge has been clarifying use (that it is not Big Brother) and getting the people supported, their families and staff on board'*. Approaches adopted by managers to increase acceptance included *'Keeping an open mind'*, *'involving stakeholders'* and *'communicating effectively with staff, service users and families'*(Focus groups).

### *Culture*

A culture of dependency and risk aversion was a significant barrier in some settings, with staff being resistant to any change regardless of what data showed was mentioned in all LAs. Assistive technology

that might support greater independence of individuals was seen as unreliable. Carers believed that AWLDs relied on 'knowing someone was there even if they did not need them'. The consensus was culture change would take time, requiring the building of trust, acceptance and engagement amongst staff members (Focus Groups).

### *Safeguarding*

While providers give examples where support was safely removed in all LAs, concerns around safeguarding of tenants persisted. In some cases the installation of JC equipment contributed to safeguarding by providing information on incidents (e.g. individuals leaving their property at night, break ins (care manager LA7)).

### *Consent*

Consent to install the equipment was not always possible as some tenants felt their privacy and personal space was being invaded and refused to have the equipment installed. Some families refused on their behalf where they were concerned, or unclear, about the aims of JR. There was uncertainty about making best interest decisions where tenants lacked capacity to consent (local authority lead, care managers LA1, 2). Providers in some areas reported adopting a pragmatic approach to consent. This included '*accepting that it is the tenant's choice on whether to install equipment in their home or room and that they capable of making that decision*' (care manager, LA7) and being '*willing to make trade-offs*' (care manager, LA1) including installation for safeguarding purposes and '*how stressed tenants would be against the benefits of installation*' (care manager, LA6).

### *Narrative around cost cutting*

Where LAs introduced JR explicitly to cut costs, families were more unfavourable and concerned their relative would lose support (care staff, LA1). There was less resistance and greater likelihood of savings being identified where commissioners and providers worked in partnership and both parties were incentivised (e.g. sharing savings; commissioners giving providers autonomy over how equipment was used; discretion on whether to reduce care packages or reallocate resources) (local authority lead, care managers, LA 3 and 4).

#### *Interpreting and using the data*

Concerns about interpreting data included complex charts in settings with a large number of residents, finding time in a busy schedule, making a routine part of job (care manager, LA3), lacking access to a computer on site, making the right assumptions about what the charts showed and the possibility that some managers might selectively interpret data (care provider, LA7). These were addressed by: managers supporting their staff to gain knowledge and skills to confidently interpret the charts (LA7, 9); JC helpline and partnership managers assisting with the interpretation of data (care manager, LA7); and support from occupational therapists (care manager, LA8). The interpretation of charts was more challenging in larger settings, being less easy to identify patterns in behaviour of individuals and care providers felt additional training was needed. JR approach is less likely to identify changes where tenants are living independently in a single tenancy.

#### *Local authority engagement*

While progress had been made in some LAs it was evident that closer partnership working between commissioners and providers supported the effective implementation of JR. JR was a catalyst in some areas for partnership working as it provides a mechanism for discussing needs of individuals. In other LA the necessary resources were not made available. For JR to work effectively providers required access to

LA occupational therapists (OT) and where not available, providers were less likely to identify potential changes. In response, JC provided OT support during the pilot, but there needs to be good local provision to embed JR approach (care provider representative, LA1). Mainstreaming of JR, including its routine use in reviews and with new tenants, and raising awareness amongst social workers about its value was identified as a challenge. There were concerns that some LAs saw JR as a stand-alone project rather than opportunity to improve their systems and policies, including changes to how they budget and commission care (local authority leads and care managers, LA1, 9).

#### *Assistive technology*

Some providers lacked information about assistive technologies available and telecare support varied by LA to support introduction of changes they identified. At baseline AT was used only with 22.8% of individuals and little indication of additional use at follow-up (care managers in focus groups, survey)

#### *Need for case studies and guidance*

Future roll out will require 'positive stories' of where JR has worked well including case studies on individuals with complex needs where managers needed to draw on wider range of evidence (e.g. reports on emotional states) to prevent incidences of disruptive behaviour (care managers, local authority leads, LA1, 3, 9).

#### *On-going monitoring*

In this pilot, equipment was installed for a limited period to identify and monitor introduction of possible changes. Providers identified the need to '*consistently review the situation using information*

*provided by JR so are able to be responsive to changing needs'* (care manager, focus group) and to identify '*how best to incorporate JR into existing review procedures'* (local authority lead)

## **Outcomes**

Care managers reported JR had supported discussions on the level of support needed by individuals.

### *Identification of change*

Potential changes to existing care were identified for a fifth of individuals (20.3%) including changes already implemented (7.8%) or planned (7.1%). However, for some individuals they were unlikely (1.6%) or unsure (3.7%) they would implement changes identified. (Table 3)

### **INSERT TABLE 3 ABOUT HERE**

In two thirds of AWLDs (66%) providers did not identify any changes because JR confirmed they were receiving the right level of support (53% of sample). The next most common reasons for not identifying changes were shared accommodation (12.6%) and a requirement to consult the commissioning authority because the support package was contractually specified (9.7%). Other factors included preferring opinions of staff, lack of acceptance of the technology and the lack of individualised data in multi-occupancy setting. Care managers yet to identify potential changes gave reasons including the need to consult partners, reassurance about reinstating existing provision if changes were detrimental, requiring additional information, risk assessments and contextual uncertainties (e.g. retendering, budgetary pressures).

### *Supporting moves to independent living*

JR confirmed the appropriateness of previously identified moves and identified individuals capable of moving into more independent living accommodation (survey data, focus groups. LA 3 and 9).

#### *Change to policies*

Some providers reported revising policies on waking night and sleep over staff and used JR as an opportunity to get *'the basics in place'*. (care manager, LA7)

### **Discussion**

Our evaluation of JR has provided new insights into the potential of using telecare to support more personalised planning of care for AWLD, and how it can support the four different types of conversations identified by Ford and Ford theory for successful culture change (initiating, specifying conditions of satisfaction, performance and closure) at commissioning authority, provider and client level. Information provided by the JC telecare system created a much needed focus for such conversations to occur. While JR model supported progression through the four types of conversations, they did not always occur at all levels necessary for sustainable change.

An opportunity for care providers to engage in conversations around understanding and set out 'conditions for satisfaction' was created at the 'Go Live' meetings, resulting in a plausible and testable theory of change. There were differences between LAs in how successful JR was in supporting cultural change and this appeared to be linked to how LA initiated conversations with providers. Resistance to change was greater where JR was introduced as part of wider narrative around cost savings, or where providers had not followed through with conversations to develop understanding with staff, service



users and their families that addressed their concerns, or where JC was used as a means to performance manage staff.

JR demonstrates the value of the information in encouraging conversations on potential change at the micro level, including designing care packages and providing important confirmation of existing care packages where needed. The identification of potential for change in 20% of AWLDs including examples of over-care, is significant. Such changes contribute meeting the 'conditions for satisfaction' identified by providers and commissioners and the wider literature on telecare including increased autonomy, quality of life, independence, privacy<sup>19</sup> and more effective use of limited resources.

There was the view amongst providers that greater familiarity of JR through longer term use, supported by case studies of complex cases and sharing learning, would lead to greater identification and implementation of change.

The holistic approach provided by JR is essential to support necessary culture change for effective use of telecare with AWLDs. Change is theorised to more likely to be successful where it is made attractive to stakeholders and is not as the result of conflicts in the system<sup>26</sup>. Our findings support this; we found that where there was a more inclusive narrative around person centred care planning at the beginning, there was greater likelihood of the intended outcomes of identifying over-care, improving quality of life and increasing independence and autonomy of AWLDs. Whereas, a more restrictive narrative focusing on cost cutting and savings was seen to be detrimental to identifying potential for change by stakeholders.

This study also provides important new insights into the use of telemonitoring as a tool for planning more personalised and appropriate care for AWLDs. It builds on previous research on how assistive technologies can support greater independence for AWLDs and be potentially resource releasing<sup>6</sup>

though our findings suggest that a limited understanding of ATs prevents take up and that more fundamental conversations around more personalised planning of care such as those facilitated by JR approach are needed to make the most of ATs.

## **Limitations**

The requirement by the University of Birmingham's Ethics Committee to use anonymised data prevented directly verifying data on individual AWLD with care managers and resulted in less contextual data being available on their homes and providers of their care. This evaluation uses a before and after design and does not provide comparative data. Other researchers have pointed out that randomised controlled trial design are often unfeasible with telecare interventions<sup>27, 28</sup> and create artificial structures limiting organisational flexibility and incremental, iterative learning valued by local managers<sup>28</sup>.

The qualitative baseline provided important insights into stakeholders' expectations and resulted in a theory of change of how the JR approach can bring about benefits to AWLDs and the care system. Some outcome measures identified by stakeholders, however, were aspirational. This study provides generalisable results of using telemonitoring to support PCP using a purposeful sample of LAs and captured important learning for future implementation. However, being a qualitative evaluation of the implementation of JR, it was not possible to quantify the frequency which issues we identified.

## **Conclusions**

This particular telecare approach offers the potential to identify reductions to the cost of care packages but has highlighted the need for telecare solutions to include a series of interconnected conversations at

service user, provider and commissioning authority levels to identify the potential for change, to obtain necessary permissions for change and requires commissioners to act as policy sponsors and have in place an adequate local support frameworks<sup>27</sup>. For telemonitoring to be an effective tool for social care of AWLDs it needs to both enable and be embedded in robust processes for personal care planning.

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## **Declaration of Conflicting Interests**

The authors have no conflict interest.

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## Contributions

All three authors were involved in all aspects of the study including conceptualisation, data collection, analyses and reporting.

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## Tables

**Table1: Number of sites and residents in the study**

Local Authority	Sites recruited	Sites who provided data	Residents (Baseline)	Residents (Follow up)	Percentage of follow up data from the largest provider
LA1	16	15	50	48	75
LA2	21	21	57	46	56
LA3	23	23	39	36	64
LA4	14	13	28	27	66
LA5	20	20	45	43	34
LA6	13	16	40	39	43
LA7	15	15	40	24	48
LA8	20	17	34	32	40
LA9	41	36	84	78	71
<b>Total</b>	<b>170</b>	<b>166</b>	<b>417</b>	<b>380</b>	

**Table 2: Number of tenants by type of accommodation and type of tenancy**

Type of accommodation	N	Per cent	
Supported living	350	83.9	
Residential home	43	10.3	3 LAs
Other	24	5.8	4 LAs
Shared tenancy	241	57.8	
Single tenancy	157	37.6	
Other	19	4.5	

**Table 3:** Identification of potential changes, actions taken and reasons for not identifying changes

Potential changes identified	N	Breakdown of actions planned and reasons given	N	Per cent
Yes	77	Implemented changes	30	7.8
		Plan to implement changes once agreed with commissioning authority and/or family	21	5.5
		Plan to pilot change and monitor using JC kit	1	0.3
		Implement in new financial year / contract	5	1.3
		Unsure will implement changes	14	3.7
		No plans to implement identified changes	6	1.6
		No	303	The monitoring information provided by JC suggests we have the right level of support
Individual has shared provision for the type of support might have considered varying	48			12.6
Required to provide a specified level of support by commissioning authority and cannot vary it easily	37			9.7
Other (specify)	35			9.2

## Figures



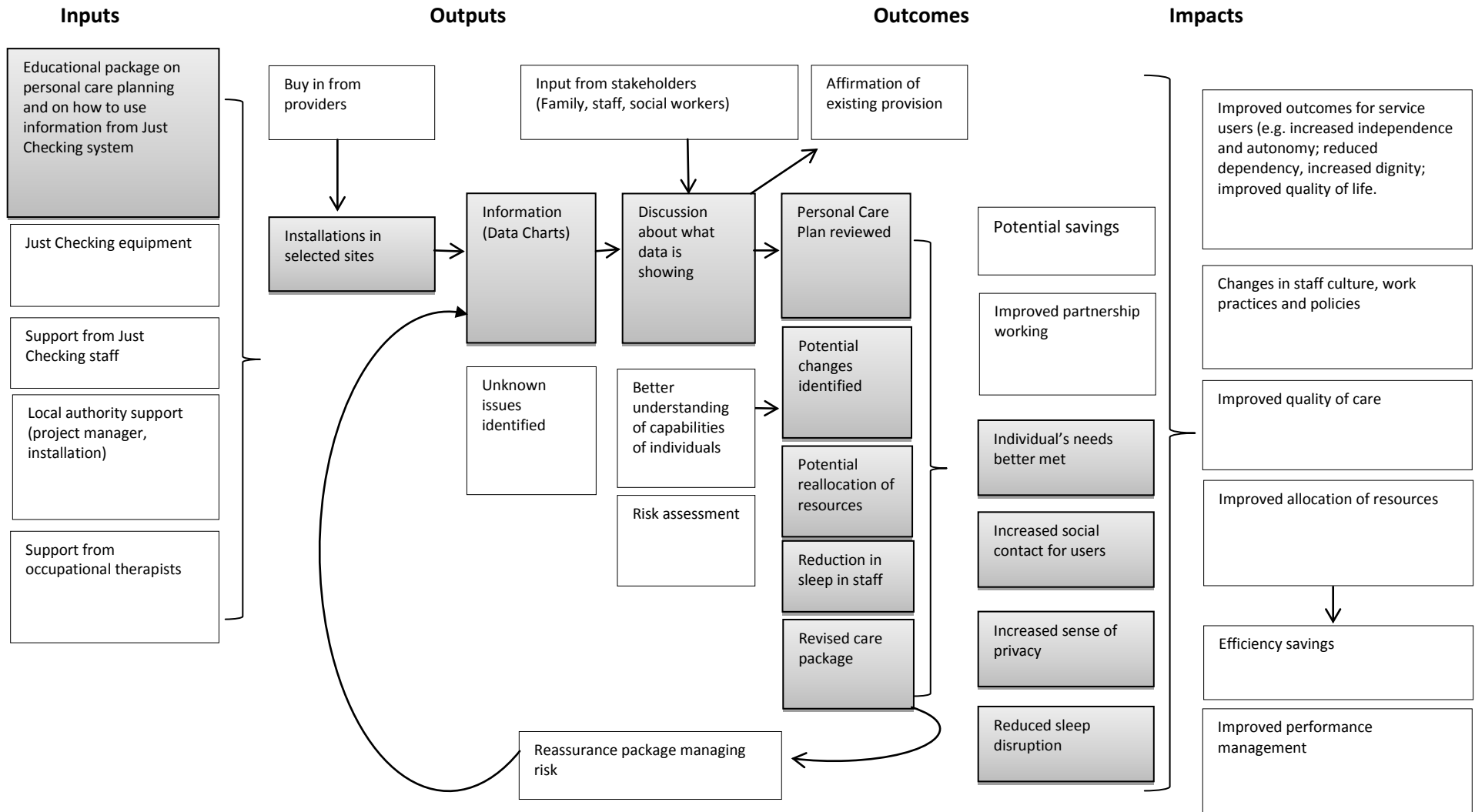


Figure1: Theory of Change for Just Right approach

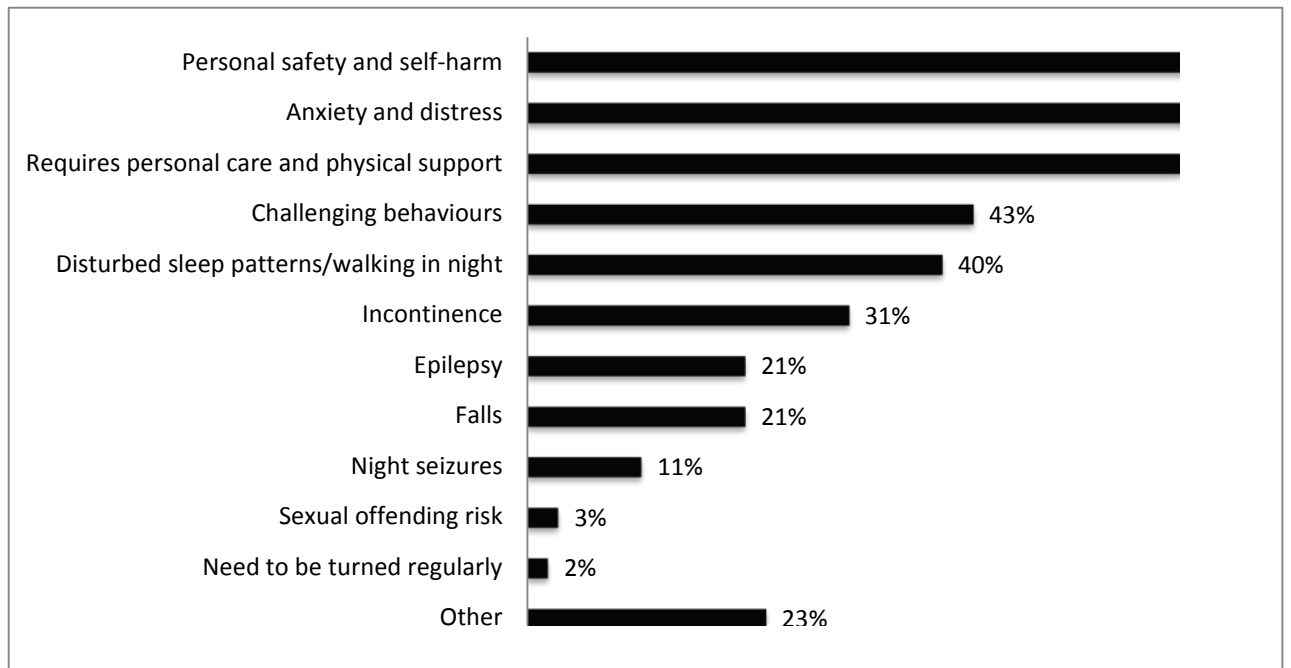


Figure 2: Reported care needs of service users

## Supplementary Information

### Methodology

#### *Online surveys*

The University of Birmingham commissioned Research Now to develop an online version of the survey tool that allowed collection of data on individual tenants at two time points from providers. The University of Birmingham developed draft questionnaires with the client and KPMG and these were tested with a small number of sites to check for ease of completion and survey burden. Feedback from these sites resulted in both a reduction and simplification of financial information collected from care managers. The survey then went through a period of live piloting with necessary changes made by Research Now before the survey was finalised. Research Now included plausible ranges and checks for the financial questions and these needed to be adjusted or removed for some questions to accommodate financial information for support packages that were outside the range of costs originally anticipated.

Research Now provided updates on which sites had completed their questionnaire twice a week to the Just Checking project manager to enable reminder emails with links to be re-sent to care managers and follow-up calls to maximise the response rate.

Originally the intention was to send out the follow up survey six weeks after the baseline survey. However, it became clear that providers were taking more time than anticipated to install the equipment, and analyse and use the data generated in reviewing care provision. A decision was taken

to use intelligence from each area to decide when providers were in a position to send out the follow up survey (in most cases this was around 3 months after installation).

*Process for ensuring anonymity of service users and settings*

It was requirement of the University of Birmingham ethics committee that the evaluation team used anonymised data. The following protocol was developed to ensure this:

- Unique identifiers were produced and used to populate individualised questionnaires for each setting.
- Each setting had its own unique link to the baseline and follow-up survey
- Each local authority had 50 pairs of links (10 for 1, 2, 3, 4 and 5 tenant settings).
- JC project manager contacted settings (thereby blinding evaluators) recruited to take part in the study and assigned links.
- JC project manager knew names of tenants and assigned a unique identifier for each tenant.
- UoB and JC project manager received regular updates on completed survey. JC project manager followed up none respondents (it was condition of participation in the study that in return for free hire of the equipment sites completed the questionnaires).
- UoB requested data set from Research Now with information removed that would allow identification of who completed the survey. Though it is possible to identify the local authority within which they are located.

**Table S1: Topics covered by baseline and follow-up surveys**

	Baseline	Follow-up
Type of setting (Residential home; Supported living; Other)	✓	
Type of tenancy (Single; Shared; Other)	✓	
Capacity of residential setting	✓	
Number of individuals currently accommodated	✓	
Week covered	✓	
Cost of all support packages in setting per week	✓	
Core Hours (number, hourly rate, total cost)	✓	
Individual hours	✓	
Waking night support	✓	
Sleep-in support	✓	
Type of assistive technology, cost per week and one-off cost	✓	
For each resident		
Individual care (hours, cost)	✓	✓
Waking night support (hours, cost)	✓	✓
Sleep in support (hours, cost)	✓	✓
Type of assistive technology, cost per week and one off cost	✓	✓
Cost of current package per week	✓	
What care needs lead to level of support provided? Respondents could select from the following: Requires personal care and physical support; Challenging behaviours; Epilepsy; Personal safety and self-harm; Anxiety and distress; Sexual offending risk; Night seizures; Incontinence; Falls; Disturbed sleep patterns/walking in night; Need to be turned regularly. They could also provide information on other needs.	✓	
Anything unusual about the [baseline] week	✓	
Person centred plan (yes, no)	✓	
Date person centred plan last reviewed	✓	
Three most important goals for tenant identified in plan	✓	
How far been able to achieve each goal	✓	
What helps achieve goal	✓	
What hinders achieving goal.	✓	
Since the introduction of JC have potential changes been identified (yes, no)		✓
Plans to implement changes where identified. Respondents could choose from following response options: 'Yes – already done so'; 'Yes – plan to do subject to agreement of LA/ family'; 'Yes – plan to pilot using JC kit to monitor'; 'Yes – but not until new financial year /contract'; 'Note sure' and 'No'.		✓
Reasons for being unable to identify any potential changes in the level of support. Respondents could select one or more of the following response options: 'This individual has shared provision for the type of support we might have considered varying'; 'Need to host a meeting to discuss with professional colleagues'; 'Need to undertake a risk assessment'; 'The monitoring information provided by JC suggests we have the right level of support'; 'We are required to provide a specified level of support by LA and cannot vary it easily'; 'We like to continue to monitor this individual longer'; and were able to specify other reasons.		✓
Planned changes in assistive technology		✓
Whether Just Checking changed the assessment of tenant. Respondents could from three response options: 'No, Just Checking has provided some information but intend to continue to monitor the individual before revising assessment'; 'No, Just Checking provided information confirming existing assessment'; 'Yes, Just Checking provided information resulted in changed assessment.'		✓
Plans for implementing new support package		✓

## Qualitative baseline: defining expectations

While there were differences between areas, a consistent set of expectations emerged:

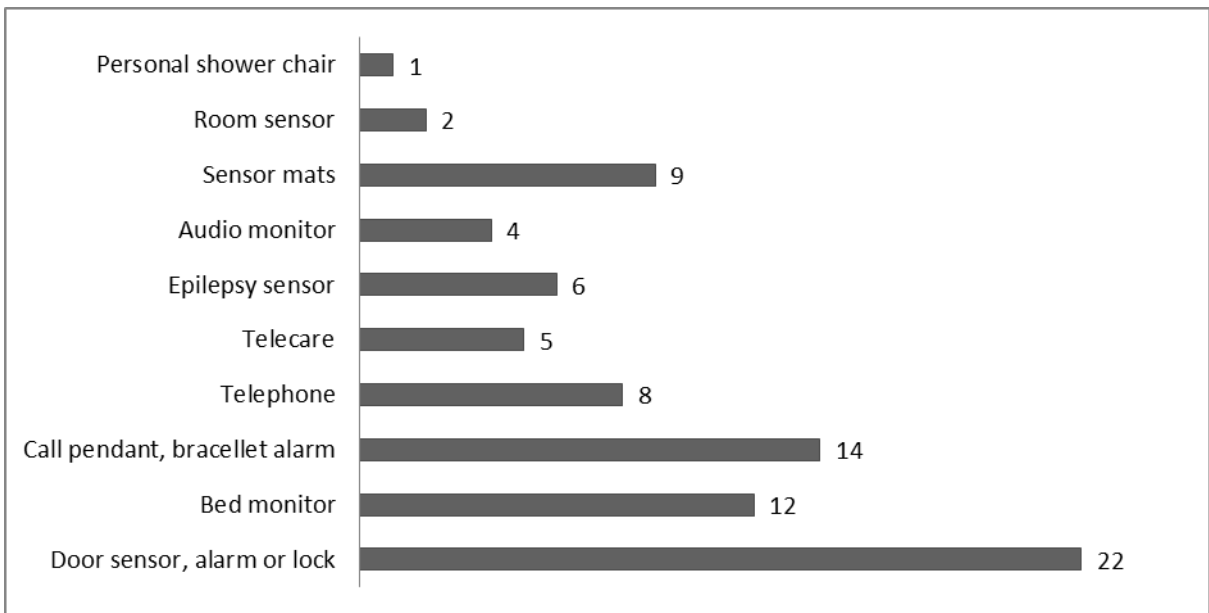
- **Objective data to make decisions** including information on activity of tenants when staff was not present.
- **Improved and more person centred support** resulting from insights into tenants' needs from activity data being used to inform personal care plans (PCP). Linked to this was **reconfiguration of support** at the individual, setting, provider and commissioning authority level and **better use of resources** with JR approach contributing to improved allocation of limited resources based on the actual needs of users. For example, removing waking night staff because tenants are not active during the night could free resource to achieved unmet needs in their PCP. JR was expected to both provide evidence that could support reducing support (e.g. identifying where staff might be safely withdrawn) and where support needed to be increased. The expectation was that JR would contribute to achieving value for money with a focus on the *'quality of support not the quantity'*.
- **Reassurance on existing and planned care packages.** JR could alleviate staff anxiety and concerns about staffing and whether the needs of individuals are were being met (e.g. by providing a more accurate view of activity during the night).
- **Sense of surveillance by tenants and staff:** While potentially positive (sense of security; *'Keeping people safe'*) there were concerns about *'big brother'* style surveillance that would need to be managed.
- **Group dynamics.** JC would provide an overview of activity over a period of time and help staff identify behaviours previously that might explain poor group dynamics (e.g. disruptive behaviour resulting in not sleeping at night).
- **Improved wellbeing outcomes for tenants** including self-worth, autonomy, improved skills, opportunities, fulfilment, happiness, social contact and being able to go out independently. Some outcomes were specific to changes that JR might identify such as removal of waking night staff would create greater privacy and better quality of life through not being woken at night.
- **Independence and autonomy** by providing evidence where and when it would be appropriate to remove care staff and with continued monitoring AWLD would have an opportunity to develop independence and confidence.
- **Support culture change** from one of staff encouraging dependency and being risk adverse to more evidenced based person centred care based on a better understanding of individual's capabilities. JR would provide an opportunity for staff to reflect, learn, to find ways to improve care including taking calculated risks and challenge existing arrangements.
- **Improve organisational reputation** through the promotion and celebration of providers using an evidenced based approach to providing support.

Outcomes for commissioners were influenced by local factors including providing evidence that some AWLDs may be in inappropriate accommodation or the need to support changes to commissioning care. Generally commissioners emphasised better allocation of resources over savings while acknowledging there was pressure to reduce costs. JR was seen as an opportunity to build a new level of trust and understanding of care needed for discussions with providers.

## **Survey findings**

### *Use of Assistive Technology*

Respondents to the baseline survey were asked to describe the use of any assistive technology for individual tenants. Only a quarter of tenants (22.8 per cent) were using any assistive technology. Responses were coded into the following categories:



**Figure S2: Reported use of assistive technology at baseline**

Ten referred to branded systems or services where it was unclear what assistive technology was being used. Twelve mentioned Just Checking itself. For 325 tenants the response was ‘none’, or ‘not applicable’, or equivalent phrases.

As in the baseline survey, follow up survey respondents varied in how they interpreted the question on assistive technology. The majority (93.7%) either did not answer the question or considered it not applicable to the tenant concerned, or referred to ‘There is no plan for assistive technology at present’. Some respondents referred to the use of assistive technology as ‘to be reviewed as part of assessment process’. There was occasional reference to changes that already had been made: ‘We have already installed bed and chair alarms to alert us of his movements as he is at risk of falling.’



*Relationship between baseline needs and identified changes*

The surveys found no clear relationship between specific needs of individuals and the ability to identify potential changes to care. Generally the ability to identify changes for each condition ranged between 16 and 22 percent with two exceptions (need to be turned regularly and risk of sexual offending). Table S2 sets out the number of cases where potential changes were, or were not identified, and number of AWLDs lost at follow up. It should be noted while overall the study achieved a reasonable sized sample, the number of individuals with each need limits the ability to draw any statistical conclusions. Also, some service users had multiple needs.

**Table S2: Relationship between needs identified at baseline and identification of potential changes**

<b>Identified need at baseline</b>	<b>Potential changes</b>	<b>No potential changes</b>	<b>No follow up data</b>	<b>Total</b>
Needs turning regularly	3 (42.9%)	4 (57.19%)	0	7
Night seizures	9 (22.5%)	31 (77.5%)	3	43
Challenging behaviours	34 (20.8%)	124 (71.1%)	14	172
Incontinence	24 (21.4%)	88 (78.6%)	11	123
Epilepsy	16 (20.7%)	61 (79.3%)	6	83
Falls	16 (20.0%)	64 (80.0%)	4	84
Disturbed sleep	29 (20.0%)	116 (80.0%)	12	157
Anxiety and distress	48 (20.8%)	191 (69.2%)	26	265
Requires personal care and physical support	43 (18.5%)	189 (71.5%)	18	250
Personal safety	40 (16.2%)	206 (83.8%)	19	265
Sexual offending	1 (10.0%)	10 (90.0%)	1	12

Supporting quotes for analysis of focus groups and open questions in online surveys

Objective data to make decisions	Better information	<p><i>'Clear picture of how people live their lives when support is not there' (Care Manager LA6)</i></p> <p><i>'We have to take people's word for what they say do and don't do, and they can give the answer they think we want to hear. I think our service users are the same - they don't want to come across as 'well I can't do that I need help, or I can manage quite well thank you'. This gives us a true, a better picture without us coming up with an idea like 'we'll come and sit with you for 24 hours'.(Care Manager, Focus Group)</i></p>
	Client movements	<p><i>The equipment has enabled us to see that the person being supported does not sleep at night and at times leaves their home late at night. This has resulted in a need to reassess their support requirements. (Care Manager LA7)</i></p>
	Use of accommodation	<p><i>The individual uses his kitchen and lounge most of the time and that has not changed in any significant way.'</i> (Care Manager LA9) and <i>'Client only uses downstairs part of the building and sleeps through the night.'</i> (Care Manager LA2)</p>
	Medication review	<p><i>This person has got some medication reviews coming up before we would need to monitor before we changed any support in service.'</i> (Care Manger LA2)</p> <p><i>'This is particularly helpful as this person has a heart condition. It is interesting to know if he has had a restless night and used to monitor sleep patterns to support care of health needs'. (Care Manager LA8)</i></p>
	Unknown issues	<p><i>'Highlighted how people sleep – had one person who does not sleep well – this was not known.'</i> (Care Manger LA5)</p> <p><i>It alerted me to level of activity in the evenings and has indicated that the person is being over-supported after 9pm at night.'</i> (Care Manger LA8)</p>
	Identified over care	<p><i>'Enabled the person we support to identify that he no longer needs all of his sleep-ins.'</i> (Care Manager LA7)</p> <p><i>'We have identified that the sleep in is not being utilised during the night we have also identified that the person is over supported after 8pm in the evening and are looking at reducing support.'</i> (Care Manager LA8)</p>
	Increase support	<p><i>The Just Checking identified that the individual was spending a long period of time alone in his property. This allowed us to increase his hours in order to support the individual to access the community.'</i> (Care Manager, LA3)</p>
	Verified staff accounts	<p><i>'Found useful to look at activities that were logged and if they actually happened and how evidenced.'</i> (Care Manager LA6)</p>
Person centred care	Reconfiguration of support	<p><i>'Delivering the right amount of support in a person centred way'. (Care Manager, Focus Group)</i></p> <p><i>'I think it turns the whole issue of care management on its head really, because your starting point is 'what are people's abilities' rather than what they can't do. So you're looking at what their abilities are what they want to do for themselves and then you're building around that' (Care Manager, Focus Group)</i></p>
	Better use of resources	<p><i>'quality of support not the quantity' (Care Manager, Focus Group)</i></p> <p><i>'I think from our perspective we are the budget holders so it's a bit about looking to see how far we can stretch that limited budget so</i></p>

		<p><i>that we can provide support to as many people as possible. And it's about making sure people are having just enough support, so that it frees up agencies to be able to offer up support to many more people.'</i> (Commissioner, Baseline Focus Group)</p> <p><i>'It's going to help us to assess what people actually need and give us confidence to remove things/support that people actually don't need, or give us evidence actually keep support that people do need.'</i> (Care provider, Baseline Focus Group)</p> <p><i>'from a care perspective, obviously there is a cause for increasing independence and choice etc for service users but from - touching on the budget - I think for us it's about hopefully using existing resources so that they're stretched a lot further so that we do actually support more people'</i> (Local Authority Official, Baseline Focus Group)</p>
	Person centred care planning	<p><i>Updated support plans to reflect the support required.'</i> (Care Provider representative, Focus Group)</p> <p><i>'Introduced personalised care plan for X to accommodate his changing needs.'</i>(Care Manager, LA5)</p>
	Made changes	<p><i>'Changed support at night to reflect better understanding of needs'</i> (Care Manager LA7)</p> <p><i>'Using the systems, we were able to see that the person supported was not using their staff at certain times of the day so after consulting with the individual and care team we were able to move the shifts to support his lifestyle and personal development.'</i> (Care Manager LA5)</p> <p><i>'We noted that Sunday hours were not being fully used as this lady was eager to spend time with mum. We took the hours from Sunday, freeing her to visit mum when she wanted, reducing the anxiety felt and used them on Wednesday to provide 4 hours for a leisure pursuit.'</i>(Care Manager LA2)</p>
Providing reassurance on existing and planned care packages	Confirmation	<p><i>'It has evidenced that the support is needed, as staff are worried about service users' safety if not supported with sleep-in support.'</i> (Care Provider representative, Focus Group)</p> <p><i>'Continually providing reassurance to both customers and staff'</i> (Care Provider representative, Focus Group)</p>
Sense of surveillance	Perceived threat / reassuring staff	<p><i>'Giving information to reassure staff'</i>(Care Provider representative, Focus Group)</p> <p><i>'Discussed with staff &amp; advised we waiting for final analysis'</i> (Care Provider representative, Focus Group)</p> <p><i>'Not big brother'</i> (Care Provider representative, Focus Group)</p> <p><i>'Movement sensor only'</i> (Care Provider representative, Focus Group)</p> <p><i>'For service user benefit not spying on staff.'</i> (Care Provider representative, Focus Group)</p>
Keeping people safe / safeguarding		<i>'Through the night time patterns of movement and the ability to check that X behaviour did not have an impact on safety - in fact there was no behaviour of concern at night reported following the system being installed.'</i> (Care Manager, LA4)
Group dynamics		<i>'develop a more creative and flexible service' that leads to 'better group dynamics in the supported environment' [By] ...filling in the gaps and grey areas a more holistic care environment can be created.'</i> (Care provider representative, baseline focus group, LA3)

Culture change	Dependency	<i>developing alternative ways of giving positive support to individuals and developing their independence'</i> (Baseline focus group)
	Risk aversion	<i>'It's evidence to back up some more positive risk taking, really, because at the moment we have to risk assess everything and you have to err on the side of caution but this kind of technology will hopefully give us that accurate ...that pin-point on what are people doing, what's the time, what exactly do they need so it will help us to implement that positive risk taking'</i> (Care Provider representative, Focus Group)
	Challenge	<i>Managers encountered situations where staff responding defensively to data that was inconsistent with their reports on users.'</i> (Care Provider representative, Focus Group)
Organisational reputation		<i>'It gives you the opportunity to dissect in every area that needs an assessment, because if you get the assessment right in the first place and get that across you'll be able to give continuity to the service user - and the story will carry on hopefully the service user will be happy with what they are getting, and the council are getting value for money as well'</i> (Care provider representative, baseline focus group)
Acceptance of JR approach	Openness	<i>Seeing what can change, be done. Looking at what care is required.'</i> (Care manager, Focus Group)
	Involving stakeholders	<i>'Meeting with families and users to address concerns'</i> (Care Provider representative, Focus Group)  <i>'Working in partnership with families and staff to support with understanding of the benefits of the trial'</i> (Care Provider representative, Focus Group)  <i>'Meetings between family and staff to review user's needs'</i> (Care Provider representative, Focus Group)  <i>'Staff on board before project starts'</i> (Care Provider representative, Focus Group)  <i>'Getting service users to help with the installation'</i> (Care Provider representative, Focus Group)
	Communication	<i>The importance of good communication could not be underestimated'</i> (Care Provider representative, Focus Group)  <i>'Good communication was important but there are still reservations around reason the equipment is here'</i> (Care Provider representative, Focus Group)  <i>'Explained about the sensors evidencing need ... works both ways'</i> (Care Provider representative, Focus Group)
Understanding how best to use the equipment		<i>'Removal of sensors where privacy is required'</i> (Care Provider representative, Focus Group)  <i>'Moved and replaced sensors to provide better/accurate readings '</i> (Care Provider representative, Focus Group)  <i>'After a while they forget the sensors are there'</i> (Care Provider representative, Focus Group)
Consent	Accepting tenants choice	<i>Accepting that it is the user's choice on whether to install equipment in their home or room and they can be capable of making that decision'. (Care Provider representative, Focus Group)</i>  <i>Some families have refused on behalf of sons/daughters</i> (Care Provider representative, Focus Group)

Local authority engagement		<i>'Rolling out and future use in the local authority will involve responding to the attitudes of other professionals who may have a different perspective to providers and response to the information provided by Just Right, in particular social workers.'</i>
Assistive technology	Awareness and availability of AT	<i>'SU is epileptic and depends on appropriate assistive technology being available'. (Care Manager, LA5)</i>  <i>'Review wake night data, look at incident forms to ensure there are no potential issues and we need to look at assistive technology to help support us.'</i> (Care Manager LA8)
	Use	<i>Removal of waking night staff and replaced with epilepsy sensor (Care Manager, LA4)</i>
Need for case studies and guidance		<i>'Develop positive stories around how JC has helped to improve service user independence', particularly for those with complex needs (Care Provider representative, Focus Group)</i>
Community engagement		<i>'Balancing community engagement with the needs and support required by users' by allowing resources within care packages to be reorganised.'</i> (Care Provider representative, Focus Group)
Continued monitoring		<i>'Once the pilot has completed may not always have the resources to interpret the data.'</i> (Care Provider representative, Focus Group)
		<i>'Consistently review the situation using information provided by Just Right so are able to be responsive to changing needs'. (Care Provider representative, Focus Group)</i>
		<i>'How best to incorporate Just Right into existing reviews procedures'</i> (Care Provider representative, Focus Group)
Importance of external support		<i>(OT) 'Very helpful and very responsive – understands system in practice.'</i> (Care Provider representative, Focus Group)
Reasons for not making changes	Contract requirements	<i>We are required to deliver the level required by council (Care Manager LA6)</i>  <i>We are required to deliver the set hours support (Care Manager LA6)</i>
	Need more information	<i>It did not give us much information as the equipment had to be withdrawn'</i> (Care Manager LA9)  <i>'We still have irregular patterns for that individual and our assessments show no pattern as of yet.'</i> (Care Manager LA3)
	Service user resistance	<i>'X refused to have the Just Checking equipment installed'</i> (Care Manager LA9)  <i>'Service user didn't like sensor in room'</i> (Care Manager LA6)
	Anxious about change	<i>'Tenant is fairly anxious at the moment about another tenants moving into the property with him. There was a tenant due to move in but the plans fell through. This could be something that could be looked into when the tenant is more settled.'</i> (Care Manager LA8)  <i>'Service user lives alone and already spends some time on his own. He is anxious at the support he receives being lowered. He will not answer the door to anyone but also will not answer the phone to anyone and communicate in any way.'</i> (Care Manager LA8)
	Vulnerable	<i>Service user is a vulnerable adult there would be risk to him spending any further time by himself than he already does. 'The other service users' needs that he shares with needs have changed and the risk would be too great for them to spend any time alone.'</i> (Care Manager LA8)  <i>'The service user is vulnerable to being exploited by others. There would be risks surrounding the household environment if left alone'. (Care Manager LA8)</i>

	Shared accommodation	<i>'Tenant is living in shared accommodation and the current package meets their needs.'</i> (Care Manger LA2)
	Already independent	<i>'Customer likes to remain as independent as possible and level of care is sufficient.'</i> (Care Manager LA3)  <i>'Service user does not have a high level of support and the support he does receive are at key points of the day that are needed.'</i> (Care Manager LA8)
	Staffing	<i>'The level of support was affected by staffing availability throughout the process due to recruitment and sickness'</i> (Care Manager LA4)  <i>'The system was in use at a time period of staff deficits, so support had to be rearranged to provide the service - recruitment and sickness the main blockages.'</i> (Care Manager LA4)
	Need to consult	<i>'Approval from LA to change the funding agreement currently in place'</i> (Care Manger LA2)  <i>'Refer back to LA regarding funding and submit our findings from Just Checking.'</i> (Care Manager LA9)  <i>'For commissioning services to recognise our findings and agree a reduction in hours.'</i> (Care Manager LA2)
	Risk assessment	<i>Ensure risk assessments are discussed and signed off by everyone involved.'</i> (Care Manager LA5)  <i>'We will need to have a robust risk assessment and protocol in place if he was to be left for any period of time.'</i> (Care Manager LA8)
Outcomes	Identification of change	<i>Change of accommodation and support package.'</i> (Care Manager LA6)  <i>'Change of accommodation. JC will help ensure this level of support is right for this person.'</i> (Care Manager LA6)
	Supporting move to independent living	<i>'Confirmed that the individual was ready for a more independent setting'</i> (Care Manager LA9)  <i>'Enabled the person we support to become more independent around the home.'</i> (Care Manager LA9)  <i>'Service user moving into single occupancy'</i> (Care Manager LA2)
	Improved quality of life  Improved sleep	<i>The data indicated that the person was having a very disrupted sleep. This lead to staff taking him to GP. The person has been prescribed sleep medication and has had a very positive impact on the person.'</i> (Care Manager LA2)  <i>'Better sleep – better quality of life</i> (Care Provider representative, Focus Group)  <i>'There hasn't been a change in the support package received; there has been a change in medication. The sensors highlighted X was awake most of the night which was causing behaviours the following day, this then triggered agitation which was believed she was a risk to the public, to ensure free from danger, and she was not supported out whilst very agitated into the community. The sensors highlighted she was up and awake most of the night in her bedroom, she closes her door of a night too, when it was highlighted the doctor prescribed sleeping tablets and changed her medication. She is a lot more calmer and now receiving correct support out in the community safely.'</i> (Care Manager LA6)