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Foreword

The Office for National Statistics has predicted a 36% growth in over 85s between 2015 and 2025, from 1.5 to 2 million across the UK, many of whom will have significant health problems. There's no doubt this will lead to a substantial increase in demand for care.

As CEO of United Kingdom Homecare Association (UKHCA), my passion is to promote high quality, sustainable care services so people know they can continue to live at home among their local community. It is universally accepted that staying at home is, for the vast majority of people, the preferred option; promoting independence, avoiding or reducing hospital admissions and keeping people in the place they know and love best and among their friends.

Our ageing population means that it's likely we, or our loved ones, will require care at some point. If you're facing the emotional decision of choosing care, or are an interested healthcare professional, you'll be keen to discover:

- · Where to find the best possible care
- How much it will cost and how to achieve the best value for money
- Whether you, or your family member or patient can stay at home, with pets, in familiar surroundings with friends or family close by

As a unique coalition of leading live-in care providers, The Live-in Care Hub is doing great work to raise awareness of this special, but still little-known service. Over the last four years it has published informative reports with original research, crucial advice and moving stories.

This, the latest report, draws on a wide variety of sources: academic research, Government reports and personal experiences. The findings may be surprising; showing that live-in care ensures a happier and healthier later life - with fewer falls - and is an excellent, affordable alternative to residential or nursing care.

This year's research, commissioned by The Hub was undertaken by the PSSRU (Personal Social Services Research Unit), a joint venture between the University of Kent and the LSE. It investigates care and nursing home fees and quality. Kent University's Adult Social Care survey was also used to compare people's happiness in care homes versus live-in care.

'Live-in', in general, allows people to maximise their quality of life, often for a similar cost to nursing homes, or less if a couple is being cared for. Financing care is a major issue and the report provides valuable insights and recommendations, as well as reinforcing the messages about the importance of planning for care in later life.

I wholeheartedly support the Hub's work in raising the profile of live-in care and the importance of helping people achieve their plans to stay at home. This report sets out many of the ways in which live-in homecare can enhance people's dignity, independence and enjoyment of life, even when health or mobility problems challenge that. It is an excellent source of information and inspiration and I'm sure it will help your search for the personal and individual care we all want.

Bridget Warr CBE

Chief Executive Officer, United Kingdom Homecare Association (UKHCA)



Care crisis

There are now 12 million people aged 65¹ or over in the UK, meaning later life care is something more and more families are having to consider.

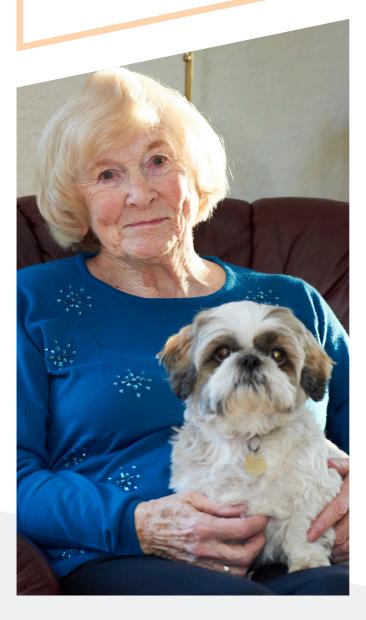
BUT, the majority don't plan for it and when loved ones require full time care it's generally needed urgently and unexpectedly². Typically, it's where a parent or relative's declining health reaches a 'tipping point', or perhaps there's a family emergency, the illness of a family carer, a fall or a hospital visit.

Desperate families often have no idea who to turn to for help, or where to go for quality information about care choices. They are often suddenly at crisis point and have to drop everything to start researching full time care. It can be an emotive and stressful time for all concerned.

The default care option tends to be residential or nursing homes, although unsurprisingly 97 per cent of people3 DON'T want to move into institutional care if they become ill or less able to cope. It can be unsettling and deeply upsetting to move away from friends, a partner or pets.

However, there is a REAL alternative. Ageing in our own home - in a safe and therapeutic environment - is the oldest and most respected form of social care. Live-in care, still little known, but fast increasing in popularity can provide the perfect solution.

Most people are at crisis point when they start looking for full time care



No pets allowed: care home heartbreak

A survey commissioned by The Live-in Care Hub discovered that shockingly, over two million people in the UK4 know an elderly person who had to have their cat or dog put to sleep, or be given away, when they moved into a residential or nursing home. The study found that 20% of elderly people would put their health at risk by refusing to go into care without their pet and 17.4% would pretend they were fine so they didn't have to go into a home and leave them.

Parting from much loved animals is one of the most distressing consequences of moving into residential care. One enormous advantage of live-in homecare is that

people can stay with the pet they adore; it is widely recognised they can help reduce isolation, loneliness and boredom in old age.

Poppy (shih tzu) has given mother much pleasure over the years and is great company for her. She is always by her side and now even sleeps in her room at night

What is live-in care?

Live-in care is just that. It allows an individual, or couple, to stay in the comfort and familiarity of their own home. They have one-to-one, high quality 24/7 support from a carefully matched carer who lives with them.

Depending on the provider and level of care agreed, core services typically include: help with mobility and safety, personal care, medication, night time support, shopping,

cooking, housework, pet care, admin, trips out and appointments, plus companionship and emotional support. Many carers are specially trained to cope with conditions such as dementia (75% of Live-in Care Hub clients live with dementia), stroke, MS, Parkinson's or palliative care.

Key benefits

Live-in care provides great peace of mind. To be in familiar surroundings, with treasured possessions, beloved pets, friends nearby, while receiving tailored, professional care enables elderly relatives to live well - and be as healthy and happy as they can be.

With no rigid timetables, each day is planned around the client and their own routines and preferences (this is especially beneficial for those with dementia). Carers can adapt quickly and easily to any changes in needs. Indeed, getting to know their charges well also helps a carer spot when someone might just be little off colour, enabling health issues to be picked up as early as possible. Live-in homecare is about caring for the whole person, not just an age or health issue.

Good carers possess a balance of dedication, reliability and compassion, combined with sociability, good humour and common sense. Hub care providers have developed proven in-depth carer-client matching procedures to Live-in carers help clients enjoy things in life that bring happiness: seeing friends, baking, gardening or reading a great book

ensure sensitive and compatible pairings. It's an essential part of making live-in care so successful.

Live-in fees can compare favourably with residential care homes, especially where couples are looked after together. Costs vary depending on requirements, for instance some people may need simple companionship and support with housekeeping, others may have complex medical needs.

Hub members are all transparent about their fees and fee structures. See pages 13 & 14 for more about planning and affording care.

Henry (golden retriever) has been such a comfort to Margaret over the years that I firmly believe he has been a fundamental influence on her wellbeing and recovery ##

It is little surprise that the Hub's survey found support for live-in care at home. Over 18% of respondents believe that those elderly people they knew would, if they were aware of live-in homecare, choose such care to remain with their pet.

Hub member care agencies say their carers help look after not just dogs and cats, but clients' pet chickens, donkeys and ponies, tortoises and even a llama in one case!

Real anguish

Up to 71 per cent5 of residential homes and sheltered housing schemes don't allow pets causing many elderly people real distress.

Being torn from a pet is hugely traumatic emotionally, but with live-in care pets can stay with their owners, avoiding the upset of rehoming, or worse, putting down their pet.

Choosing full time care

Knowing how to decide on care isn't easy, especially when it's needed urgently or when a loved one is in a vulnerable condition.

To give the latest insight on the care market and to reveal more about families' experience of finding full time care, The Live-in Care Hub commissioned brand new research from the world renowned Personal Social Services Research Unit (PSSRU), a collaboration between the University of Kent and the LSE⁶. Its 'secret shopper'

research looks at price and quality across English care homes. The Hub has compared and contrasted the findings with its own vast knowledge of live-in as an option and lastly, combined these with intelligence from the authoritative **Care Homes Market Study 2017**⁷ to identify the following key factors to consider.

Care considerations



1. Word of mouth: Asking trusted friends and family for advice on their own experience of choosing care⁷ reassures people in a world of hidden costs, lack of information and generally very limited time in which to research and organise everything.



2. Distance from home: Naturally, people want to stay close to friends or family but when investigating care homes, most people look within just 20 minutes' drive from home. This significantly reduces choice given 19% of postcode districts? have only two, or fewer, care or nursing homes within a 15-minute drive time. Obviously, with live-in care this isn't an issue.



3. Value for money: The research shows that live-in care is on a par with many care and nursing home fees, especially in the South East and London. More information about costs and financing can be found on pages 13 and 14.



- **4. Quality of care:** Good care should enable people to maintain the best possible quality of life, for as long as possible, but...
- More than 50% of homes do not allow people to keep their pets⁶; whereas with live-in care pets are part of the family – and stay that way.
- More than a quarter of care homes don't let residents leave the grounds⁶; but with live-in, clients are free to go out and about wherever and whenever they want their carer can always go with them if desired
- Only 40% of care homes can guarantee residents won't have to move out if their condition deteriorates⁶; in most cases live-in care clients enjoy packages that evolve to meet their needs until the end (in fact a large majority die at home or within 48 hours of going into hospital).



5. Cleanliness, friendliness and homeliness: Everyone wants to live somewhere that feels like home, rather than an institution. But while functional needs are easily achievable (more than two thirds of care and nursing homes are clean and comfortable say residents⁸, with 70% saying all their needs are met), it's the *feeling* of being at home that's harder to capture. This is a key part of people's happiness.

Low expectations and pressure to make decisions quickly means people often accept the first home that is 'good enough'



6. Staffing: While in a care or nursing home there may be numerous staff (ratios range from three residents to one carer; to eight or more residents to one carer), one-to-one time is normally strictly allocated and it's rare to have three hours or more a day⁹. It's therefore harder for care home staff to give the level of care they might. Live-in carers however are there 24/7 to give individual, one-to-one, personalised care – a key reason behind live-in's much lower recorded rates of falls and hip fractures – a crucial safety and

Shockingly, "low expectations and pressure to make decisions quickly means people often accept the first home that is 'good enough'¹⁰." The Live-in Care Hub recommends advance care planning to avoid the 'good enough' decision and achieve the 'perfect for me' scenario.



Falls - the quiet menace

They sound relatively innocuous, but every minute, six people over 65 suffer a fall¹¹ and falls and fall-related injuries are a common and serious problem for older people. 30% of over 65s¹² and 50% of over 80s fall at least once a year, and eight per cent of the 80+ population in England and Wales were admitted to hospital in 2014.

Due to their age, advanced frailty and medical conditions, people who are in a residential care or nursing home, or who have live-in care at home are among the group with the highest risk of falling. In fact, a major reason for someone needing to have full time care is a fall, or a history of falls

The worst falls result in serious injury, including hip fractures of which there are about 60,000 a year (across all ages) in England, Wales and Northern Ireland (excluding Scotland). According to the Royal College of Physicians: "hip fracture patients face a significant risk of dying or of losing their independence."

A month after suffering a hip fracture one in 12 people will have died¹³ and only half will have returned home. The annual cost for all hip fractures in the UK¹⁴, including medical and social care, is about £2 billion.

Almost ONE THIRD fewer falls: Live-in care vs care from residential care and nursing homes.



Live-in care at home - one fall every 1.09 person years¹⁶





Residential care & nursing homes - one fall every 1.2 - 2.2 person years 16.17.18.19

Cost to the NHS:

- Each hip fracture likely to need hospital admission costs £5,744 per patient¹⁹
- Each ambulance call-out costs £230²⁰
- Falls account for up to 40 per cent of ambulance call-outs²¹ for people aged 65+²¹
- Falls are estimated to cost the NHS more than £2.3 billion per year²²
- Social care costs are 70 per cent higher²³ in the year following a hospital admission for a fall than in the previous year

The data certainly suggests live-in care is associated with fewer falls than in residential care, perhaps because of the opportunities to be more active and engaged in self-care and the ethos of moving more, sitting less

Professor Dawn Skelton,Glasgow Caledonian University,
an expert on falls



People living in a residential or nursing home can expect to **fall at least one and a half times a year**. With live-in care, this statistic is lower, with one fall a year.



People are nearly a **third more likely to fall** in any one year if they're in a residential or nursing home, compared to living at home, with live-in care.

Why do people fall?

The impact of falls increases with age and some conditions such as dementia, Parkinson's or stroke can pre-dispose people to the risk.

In elderly people, falls are most commonly caused by weakness and lack of agility. If you are too weak or lack the agility to recover after you stumble, you are more likely to fall. Obviously, medical issues are also frequently the cause and include confusion, dementia, cognitive and functional impairment including stroke, not eating enough before bed (causing low blood sugar in the morning), postural hypotension (low blood pressure and dizziness when getting up). Poor eyesight, inner-ear problems, sedation and psychoactive medications also are common causes.

Urinary tract infections (UTIs) are also a frequent cause of falls in older people as they can cause acute confusion and unsteadiness. Carer vigilance means these can be managed very well at home and helps in preventing falls.

A live-in carer will give his or her client enough to eat and drink and will encourage someone to do as much activity as possible. This will include such simple exercise as getting in and out of a chair and walking about, which maintains strength and agility - leading to fewer falls.

Hip fractures - and shattered lives

Every year, 5,000 people die shortly after a hip fracture - that is more than one person every two hours. Hip fractures are the commonest cause of injury related death.

Nearly one in five of those accidents take place in residential or nursing homes²⁴.

HALF as many hip fractures:

Live-in care vs care from residential care and nursing homes²⁵.



Live-in care -

a **1.7%** chance of having a hip fracture²⁵ in any one year



Residential care & nursing homes -

a **3.2%** chance of having a hip fracture²⁵ in any one year

Preventing and avoiding hospital admissions

Along with hip fractures and other injuries, falling also affects family members and the carers of people who fall. It has an impact on quality of life, health and healthcare costs.

People often experience a loss of independence and confidence after a fall and some become housebound. This is a vicious circle because anxiety about the fall, pain and lack of activity can reduce quality of life further and make people weaker and often more vulnerable to further falls.

It's a massive problem that can only increase with an ageing population - but live-in homecare can reduce the incidence - and a growth in the sector can deliver a real cost saving in both human and financial terms²⁶.

Clients with live-in homecare experience far fewer falls and consequent hospital admissions. And, even if someone has been in hospital, they are able to be discharged quickly and rehabilitation at home is far less traumatic and more comfortable in familiar surroundings. There's also less chance of contracting the ever-present risk of a hospitalacquired infection.



Savings for the NHS

Live-in homecare offers an effective solution to the issue of hospital bed blocking, which currently costs £900m a year for NHS England alone (BBC Feb '16). Early discharge from hospital is thought to save around £700 per bed per night. Live-in homecare means clients have an evolving personal care plan and ongoing bespoke, person-centred attention means they're far less likely to suffer from falls. This releases pressure on NHS A&E departments and significantly mitigates the risk of readmission.

Avoiding emergency hospital admissions is a major concern for the National Health Service (NHS), not only because of the high and rising unit costs of emergency admission compared with other forms of care, but also because of the disruption it causes to elective health care - most notably inpatient waiting lists - and to the individuals admitted.

Staying safe and well at home is the best solution for people, their families and communities. Live-in homecare has an essential role working with the health service. It can make a real difference to avoiding hospital admission, which is traumatic for anyone, but particularly for people with dementia or advancing frailty

Bridget Warr CBE,

Chief Executive, United Kingdom Homecare Association

The happiness survey

Anecdotally, it's recognised that the freedom of being able to ask for a favourite meal, see a football match, sit with a much-loved pet, listen to a story, or be taken to the seaside on a sunny day means quality of life is truly enhanced.

Live-in care honours dignity and independence. It offers the least restrictive environment for people as they age, with none of the rules associated with institutionalised care. Home care is personalised as no one person is the same. It can truly enrich quality of life.

The Live-In Care Hub's quality of life study²⁷ backs this up. As people get older, weaker and less active, and especially where they have medical conditions, the simple things, such as food, drink and a sense of independence often become life's most important aspects. Having tasty, nutritious meals can become a highlight of the day, while conversely, meals that are unappealing or of low quality can make eating a tedious and unpleasant chore, risking a further decline in health.

- **39%** of those in residential care and OVER HALF (53.5%) in nursing homes NEVER LEAVE THEIR HOME, compared with just one in seven (**14**%) live-in
- 98% of live-in clients say the care and support they receive helps them have a better quality of life

Happiness is NOT a luxury – everyone needs it!

- 97% do at least some of the things they value and enjoy (despite many being sick, frail and close to the end of life)
- 5% of those in residential care and one in eight (11%) in nursing homes say they don't do ANYTHING they value or enjoy with their time



Real lives

Val Doonican's story

Household favourite Val Doonican, graced TVs and pop charts for over 25 years. A strong family man, his marriage to fellow entertainer, Lynette Rae, spanned 54 years. They had two daughters - Fiona and Sarah – who, in 2013 noticed their parents were becoming increasingly frail. Val was a carer for Lynn, who had Alzheimer's and arthritis, but he also suffered a series of illnesses. It was clear they needed extra support.

The family opted for live-in care. Fiona recollects that within a few days her parents were used to it: "They thought it was amazing. They were being cooked delicious meals, brought cups of tea and cared for, in their own home and to their own timescales."

In 2014 Val had a series of mini-strokes and went into a specialist nursing home to recover. Lynn remained at home with carers, who made sure she could visit Val regularly. Sadly, six months later in July 2015, Val passed away. After being married for 54 years, Lynn missed him terribly, but her carers remained at her side to provide much-needed consistency and care.



Rachel's care journey

When Rachel became increasingly frail, her family put her Devonshire house on the market and moved her to a care home near them in Luton, but, with demanding jobs and a large family it was difficult to visit as often as they wanted.

Rachel felt lonely and institutionalised and started going visibly downhill - until her son and daughter in law discovered live-in care. One of The Live-in Care Hub's member agencies quickly organised Lisa, an experienced carer to move in so Rachel could return home after all.

Able to see her friends regularly, attend her local church and history society meetings again, the improvement in her happiness and wellbeing was rapid and sustained - and her family are reassured that she is in the best possible hands.

One thing at the forefront of our minds was that we wanted to treasure their last years and have wonderful memories of our parents, helping them to maintain their dignity, together, in the home they loved. They both just adored their carers; I have recommended live-in care to so many people

Fiona Doonican

Staying together

Margaret was diagnosed with Brown-Sequard Syndrome, a condition of the spinal cord, 20 years ago, tragically just as her husband passed away. Some 10 years later an operation to improve things went badly, leaving her with no feeling in her left leg and constant pain and sensitivity in the other one.

However, she is a brave lady who's been helped significantly by live-in care. The former specialist paediatric physio, who changed children's lives at Addenbrookes Hospital and was also a tennis coach has managed, as far as possible (with the help of her carer), to maintain her independence and a busy social life. Indeed, that's how she met Hugh, a wonderful man with whom she has lived for the past six years (plus his springer spaniel, Jack). They recently married and, because her husband is rather frail, sharing a carer is the perfect solution for them; it has enabled them to build a happy life together.

The pair's respective sons and daughters live many miles away and have busy family lives, so live-in care means they can stay close to good friends and everyone is free from worry.

Full time care: the costs

Most people only know about residential care or nursing homes, but The Live-in Care Hub is passionate about raising awareness of care at home as a real alternative. It generally offers a better quality of care and is often in a similar price bracket, or significantly lower where a couple stay together and are cared for together.

In The Live-in Care Hub's specially commissioned report: Price & Quality Across English Care Homes (published in partnership with the University of Kent and the LSE's joint Personal Social Services Research Unit⁶) undercover research was undertaken by 'secret shoppers'. They surveyed price and quality across 1,022 care and nursing homes for three different scenarios of the most common reasons people need full time care.

The report found that the average price for live-in care is £1,080 a week. When that's compared with nursing homes across the country (a large proportion of people with live-in care would otherwise be in nursing homes), a third of them charge £1,000 or more a week. Looking at London and the South East, live-in care is under a quarter more expensive than the average cost of all residential care.

- Nationally, a third of nursing homes cost £1,000 a week or more and 10% of care homes cost over £1,000 a week⁶
- In the South East, the average price of residential care is £901 a week, with 64% of nursing homes costing £1,000 a week or more⁶
- In London, half of all nursing homes cost £1,000 a week or more, and a quarter of care homes cost this much
- In contrast, the average cost of fully managed 24/7 livein care for someone with dementia, who would otherwise need to be in a nursing home is £1,080 a week⁶

The investigation also confirmed that:

 Nursing homes are significantly more expensive than care homes, even though the conditions described in the

- secret shopper exercise are not necessarily more work for the care home. Live-in care fees are no higher for a 'nursing home' condition than a 'care' condition.
- A diagnosis of dementia leads to higher fees for both care homes and live-in care due to the increased support required
- There is great regional disparity in fees homes in London and the SE are much more expensive than in other parts of the country. Live-in fees are the same throughout the country

Some care homes are clearly excellent; they allow pets, or allow pets to visit, residents can pop out when they want (health permitting), they're friendly and engaging on the telephone and say the client wouldn't have to move elsewhere if their condition deteriorated. **However, they are relatively rare**: just 7% of the care home population. They cost an average of £893 a week (which means half cost more than that), with 33% charging £1,000 or more a week.

All other things being equal, the study found that excellent live-in care agencies offer the same or more than residential care homes: they allow their clients to have pets, allow pets to visit, allow their clients to go for a walk when they want, are friendly and engaging on the telephone and their clients do not have to move if their condition worsens.

The cost of a medical appointment

A third of care homes charge extra³¹ for a carer to take their client to the doctor or hospital.

look after their client if they need a hospital stay.

This can be a massive relief for families, especially those who don't live nearby and for whom visiting regularly and getting to speak to medical staff is difficult.



Financing care

In recent years, the criteria for obtaining state funding for care has been tightened and far fewer people are now eligible. It's certainly worth exploring state funding - both with local authorities and with the NHS - but in most cases, it's likely that at least an element of care will need to be privately funded. Whatever type of care is required, making early saving plans is essential; costs will inevitably add up and it will be expensive.

A survey found that only 27% of the population³⁰ had planned how they would fund potential care (something 75% of people are likely to need at some point), while 60% of women have planned their wedding before even meeting their potential groom.

The key considerations will be different for each person to ensure the desired balance of quality of life alongside financial constraints, as well as how long care is likely to be needed and whether full or part time is appropriate. Family members may also be available for additional support; if family can help one week out of four, that cuts the cost by a quarter - flexibility that's not possible in a care home.

It is certainly worth talking to a financial advisor who is SOLLA (Society of Later Life Advisors) qualified as well as checking fees upfront to clarify actual charges, rather than just percentages. The Live-in Care Hub is also a great source of impartial advice about arranging care for each individual circumstance.

Further information

If you would like to find out more about 24/7 care, The Live-in Care Hub is an invaluable information resource that shows how, with the right professional support, loved ones can stay in their own home, often right through until the end of life.

Website: www.liveincarehub.co.uk
Telephone hotline: 0330 311 2906
Email: hello@liveincarehub.co.uk
Messenger: m.me/liveincarehub

Live-in care - find out more

Live-in homecare options

There are two models of live-in homecare: full management and introductory. Some of The Live-in Care Hub's members offer the former and some the latter - and a few offer both.

With full management, the company providing the care employs and trains its carers and oversees all aspects of care. It suits families with significant other demands on their time, or those living some distance away.

An introductory care service is where agencies do not employ carers directly. They match clients with carers and provide training. Their carers are responsible for their own tax and NI contributions and are paid directly by clients or their families. This care option is appropriate for those families able and keen to be more closely involved.

The Live-in Care Hub the guiding light for live-in care

Founded in 2013, The Live-in Care Hub is a non-profit organisation committed to creating awareness of 24/7 care at home and therefore raising the quality of care in the UK.

As the expert in live-in care, The Hub guides families through all the options in an honest, impartial way. It's all about offering an enhanced life at home that challenges the traditional view that residential care homes are the only answer.

All the Hub's care providers are also members of the United Kingdom Homecare Association. Both organisations share a vision to guarantee the very highest standards of care.

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- ^{25.} Johansen, A, Boulton, C., and Neuberger, J (2016). Diurnal and seasonal patterns in presentations with hip fracture—data from the national hip fracture database. Age and Ageing 2016; 45: 883–886. From this study we see that 12,141 hip fractures took place in 2014 in England, Wales and Northern Ireland. Competition commission research shows that there are 376,607 people in care homes in these countries. Therefore, there is a 12,141/376,607 = 3.22% chance that any one person will have a hip fracture. In live-in care, using data collected by The live-in Care Hub over 2018, 25 people out of 1,409 had a hip fracture = 1.7% chance of a hip fracture.
- Research conducted by One Poll, July 2014, for live-in care providers Consultus Care.
 A survey investigating the quality of Live-in Care Hub's clients using the ASCOT (Adult Social Care Outcomes Toolkit) Survey technique, developed by Personal Social Services Research Unit, University of Kent. 293 responses. Compared to Personal Social Services Adult Social Care Survey, England 2016-17
- 28. Ipsos MORI



