PUBLIC HEALTH

Joint Strategic Needs Assessment (JSNA)

Unpaid Carers Needs Assessment

2. Appendix

East Riding of Yorkshire Council
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EAST RIDING OF YORKSHIRE COUNCIL

East Riding of Yorkshire Council, Joint Strategic Needs Assessment (JSNA)
Unpaid Carers Needs Assessment - Appendix File

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Appendix 1. Mini Literature Review

A precis for each of the individual papers that were selected to form a mini literature review on the subject of the effect of caring on carers' wellbeing, are given below. For a summary of these, please refer to section 4 (page 12) in the main carers' needs assessment document.

1. **Heslin, M., Forster, A., Healey, A. and Patel, A. "A systematic review of the economic evidence for interventions for family carers of stroke patients." Clinical Rehabilitation 2016, Vol. 30(2) 119–133**

Although the number of salient papers was not large (10), those that showed positive effects were:

Grasel et al - no differences in carer or patient outcomes in 6 months but longer term effects claimed through reduced institutionalisation and mortality.

Pierce et al. – "Caring-Web" no significant differences between intervention and control groups in depression and life satisfaction. However, the conclusion is that the intervention helped carers make informed decisions about health care needs of stroke survivors, which can be evidenced to save money.

Kalra et al.
Patel et al. – Carer training (vs conventional care on stroke wards aimed at carers). Carers and patients in the intervention experienced less anxiety, less depression and better QoL. Carers also experienced less burden. The conclusion was that training carers during patient rehabilitation reduced costs and carer burden and improved psychosocial outcomes at one year.

Mant et al., - Family support organiser (vs normal care group) aimed at carers. Better outcomes on a number of specific measures (e.g. Frenchay activities; SF-36; Dartmouth co-op charts). The conclusion was that family support significantly increased social activities and improved QoL for carers. No significant effect on patients.

Clinical Messages for this review:

- Few studies have conducted economic evaluations of interventions for informal carers of stroke patients.
- Of the studies that have conducted full economic evaluations, there is some weak evidence that these interventions (caring-web and carer training) are effective and cost effective.

2. **Oishi, A. and Murtagh, F.E.M. "The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals." *Palliative Medicine* 2014, Vol. 28(9) 1081–1098**

This paper is focused on the primary care teams that are available to support patients and carers at home with the conclusion that this group expect compassionate care from the GP. The two main

challenges were: how to maintain continuity and how to deal with the uncertainly in non –cancer illnesses. Patients did not express any expectation of primary care nurses which would suggest they don't know that they are part of a team that could provide this.

3. **Ventura, A. D., Susan Burney, S., Brooker, J., Fletcher, J., and Ricciardelli, L. "Home-based palliative care: A systematic literature review of the self-reported unmet needs of patients and carers."**

There are a number of studies focused on patients and these are not included in this review summary (out of scope).

Decker and Young (1991) - Carers frequently expressed a need for respite care and for more information regarding what to do at the time of death.

Hudson (2004) - About a quarter of carers felt areas of difficulty were continuity of care, inadequate information, limited respite and lack of symptom management education.

Osse et al (2006) - About a quarter wanted to receive more professional attention to make them more competent at care giving.

About a fifth of caregivers wanted more professional attention for fears about unpredictable future (including finances). More than half wanted more information about alternative medicines and euthanasia.

Murray (2004) – Spiritual needs were unmet for both patients and carers. Spiritual concerns of lung cancer patients and their carers was characterised by despair, punctuated by episodes of hope and striving to maintain a positive outlook.

Spiritual concerns of heart failure patients and their carers were characterised by hopelessness, isolation and altered self-image. Patients maintained a brave face so as to not upset others, therefore spiritual needs went unrecognised.

4. **Nadia E. Crellina, N. E., Martin Orrella, M., McDermotta, O. and Charlesworth, G. "Self-efficacy and health-related quality of life in family carers of people with dementia: a systematic review." Aging & Mental Health, 2014 Vol. 18, No. 8, 954_969**

Caring for an individual with dementia, is associated with depression, anxiety, greater risk of hypertension and heart disease, decreased immunity and higher mortality.
Mixed valence – i.e. positive and negative emotions co-existing recently well recognised. These positives are: role enjoyment, positive affect, satisfaction, role gain, uplifts, rewards, accomplishment, growth and meaning. These may be independent of the negatives. Traditional model of stress-coping by Lazarus and Folkman (1984) do not contain any positive elements. The stress-health framework (Schulz and Salthouse 1999) recognises mixed valence.

This review has found that the positive and negative, instead of being independent. They are inter-related.

Self-Esteem as measured by the Heath Related Quality of Life is shown to be domain specific e.g. important in obtaining respite, responding to disruptive behaviour and controlling upsetting thoughts.

The review does not contain information on the following that have been shown to be important in carers: coping, perceived social support, social networks and coping strategy.

Self-esteem is a modifiable construct and might inform future support for carers.

5. **De Guzman, A. E. "Concept of Care, Caring Expectations, and Caring Frustrations of the Elderly Suffering from Chronic Illness." Educational Gerontology, 38: 299–313, 2012**

The physical environment influenced patients' experiences of care and being cared for in four ways:
(a) it was a symbol of death and dying,
(b) it contained symbols expressing messages of caring and uncaring,
(c) it influenced the balance between interaction and privacy,
(d) it contained objects that could facilitate a shift away from self.
(Edvardsson, Sandman, and Rasmussen (2006).

Also, the importance of an open communication between the carer and the cared-for frequently appeared in the field texts. Noddings (2002) identifies dialogue as the most fundamental component of the care model.

Caring expectations are personal concepts that vary from person to person – this study suggests two distinct dimensions: visibility and presence.

a) Visibility – affirms to the cared for that they are indeed being cared for
b) Presence – focuses more on the carer's intrinsic qualities e.g. commitment, competence

Caring frustrations are subdivided into 2 themes: deprivation and depreciation.

a) Deprivation e.g. financial constraints and inadequate facilities – this can lead to feeling like a burden and having to be eternally grateful.
b) Depreciation – a loss of function or autonomy – this can lead to violation of personal integrity. Through hopelessness, uselessness, weakness and meaninglessness. These challenge the self-identity and self-image of the person.

The cared for subjective concept of care should particularly be noted.

Caring frustration is inevitable, but proper identification of the cause of dissatisfaction can lessen the suffering of the cared-for.

6. **Hammond, T., Weinberg, M. K., Cummins, R. A. "The dyadic interaction of relationships and disability type on informal carer subjective well-being." Qual Life Res (2014) 23:1535–1542**

It is well documented that informal carers report increased symptoms of depression, psychological distress and lower perceptions of self-efficacy and subjective wellbeing. One variable that is seen as important is the intensity of the caring responsibility – amount of time, number of tasks and problem behaviours of the cared for have all been show to make up perceived burden. High intensity is associated with high distress.

Comparative analyses have demonstrated that when controlling for socio-economic factors and care intensity, carer givers with cancer or dementia report higher levels of burden and psychological distress compared to those supporting someone with a chronic health condition or frail older individuals.
Family members report more stress and sadness than non-family individuals.

More recent evidence suggests that caring for a spouse poses the greatest risk of burden, depression and diminished subjective wellbeing when compared to caring for a child, adult child and parent.

The subjective wellbeing of carers appears to be chronically low, indicative of homeostatic defeat. Those caring for a child with a mental illness or multiple types of disability were found to report the lowest levels of subjective wellbeing across all groups. The presence of complex, non-finite grief and the challenges of raising a child with a disability may overwhelm coping resources.

Carers' discrepancy with the general population on satisfaction and achievement in life was also clearly seen.

7. **Figueiredo, D., Gabriel, R., Jacome, C., Cruz, J and Marques, A. "Caring for Relatives with Chronic Obstructive Pulmonary Disease: How does the disease severity impact on family carers? Ageing and Mental Health, vol 18, No. 3, 385-393 (2014)**

Used Hospital Anxiety and Depression Scale and Carers' Assessment of Difficulty Index – 167 family carers.

The CADI looks to be in interesting scale with items such as The person I care for sometimes manipulates me; it is physically tiring; it restricts my social life.

Those caring for those with advanced COPD reported feeling more stressed and experiencing more depression and worse self-reported mental health. COPD severity was a significant predictor of Carers' subjective burden.
Frequency of anxiety was similar in early and advanced COPD carers. The strain on the family system might be affected the frequency of transitions between crisis and non-crisis and ongoing uncertainty of when crisis will occur and end.

Helping carers to find meaning in their caring role should be encouraged as this has been associate with improved carer wellbeing, successful coping and attitude toward the future. (Tarlow et al., 2004).

Raising of community awareness for availability of respite services is fundamental to prevent fatigue and enable self-care (Simpson et al, 2010).

Interventions to support interventions tailored to the specific demands of COPD care giving and delivered earlier in the care-giving trajectory.

8. **Gilbert, E., Usher, J.m. and Perz, J. "Not that I want to be thought of as a hero": Narrative analysis of performative masculinities and the experience of informal cancer caring. Psychology and health (2014) vol. 29, No. 12, 1442-1457**

Ribeiro and Paul, 2008 – men may find it particularly difficult to adapt to a caring role due to socially constructed gender expectations that position caregiving as a feminine practice.

Maughan et al., 2002 and Russell, 2001 – men enact a gender-specific style of care-giving, features of which are: strength, machoism, rationality, courage and instrumentality.

Calasanti and King (2007) – men's dominant approach to care was rational, task-based and showed emotional strength. They reported needing to block negative emotions such as guilt or depression by drinking, taking seeping pilss/anti-depressants.

Lethborg et al, 2003 – Men did experience a crisis and trauma following partners' diagnosis but subordinated their own shock and trauma and took control by assuming the role of comforter and protector. This led to many men feeling helpless, bewildered, lacking in support and unacknowledged. This dynamic was found to be co-constructed in heterosexual couples with women partners expressing emotion and men being stoical and strong.

Ribiero and Paul, 2008 - social value of the caring role increases when performed by men and is seen as more deserving of greater recognition and acclaim and is deemed more heroic than if performed by women.

Manne et al., 2005 – relational communication patterns are associated with levels of coping and psychological distress in couples living with cancer – avoidance of communication results in lower relational satisfaction and higher levels of distress (Perz et al., 2011).

Ussher et al., 2011 – Couples who are mutually attentive, recognise the needs of the other and who openly communicate are more able to engage in effective coping styles leading to positive experiences e.g. increased relationship closeness.

9. **Cairns, D., Brown, J., Tolson, D. and Darbyshire, C. "Caring for a child with learning disabilities over a prolonged period of time: An exploratory survey on the experiences and health of older parent carers living in Scotland. Journal of Applied Research in Intellectual Disabilities (2014), 27, 471-480**

Conclusion – As the number of older parents caring for their dependent offspring at home increases, there is an urgent need to review how parent carers and their children are supported in later life. Mechanisms to monitor changing needs over time are required that reflect the demanding role raced by ageing parent caregivers.

People with learning disabilities are living longer and and increasingly developing age-related conditions such as dementia (Llewellyn, 2011).
Older parent carers are not only experiencing their own conditions associated with ageing but also those of their children with learning disabilities.

Those providing care over a long period of time – mental and physical health likely to deteriorate the longer the carer has been caring (Carers UK, 2012).

Economic contribution made by carers in the UK is £87 billion per year (carers' UK, 2008).

Murphy et al., 2007 – five themes emerged from caregiver experiences: stress of caregiving, negative impact on caregiver health, sharing the burden, worry about the future and caregiver coping strategies. Caregivers also overlooked their own health problems and were more concerned about their children with a learning disability and the family as a whole. Many carers were also concerned of the impact of their own deteriorating health on their ability to continue the long term needs of their children.

Overall – physical health of these carers were similar to UK norms for the young old and middle old, but not for the old-old. Parfent carers' overall MH was below UK norms for all age groups.

2008 Carers' Week Survey – 95% of those questioned said they regularly disguised the fact that their health was suffering in order to continue their caring responsibilities.

10. **Moore, C. R., Martin, A. S., Kaup, A. R., Thompson, W. K., Paters, M. E., Jeste, D. V., Golshan, S and Eyler, L. T. "From suffering to caring: a model of differences among older adults in levels of compassion." International Journal of Geriatric Psychiatry (2015); 30:185-191**

1000 50 – 99 year olds – in-depth survey of compassion, resilience, past and present stress and emotional functioning.

Found – Female gender, greater resilience and more stressful life events were related to higher self-reported levels of compassion. Older women report more compassion than older men. Resilience and significant life events independently appear to facilitate a desire to help others whilst current stress and past and present emotional functioning are less relevant.

Interventions that capitalise on associations between resilience and compassion should be tested wither by promoting caring acts or by fostering resilience. Stressful events in later life may be capitalised upon as opportunities for personal growth or mastery.

Stellar et. al., found lower income, education and job status relative to one's peers, exhibited greater compassion toward others than upper-status individuals in terms of self-reports of compassion and physiological responses.

This finding has been supported by national surveys showing that the poorest fifth of the USA donates the largest percentage of their income to charity (Greeve, 2009); Piff, et al., 2009).

Gender differences have been found in younger adults (Mercadillo, et. al., 2011) with a tendency to find greater compassion among women.

Viewing selves as caring is important to many women's self-concept BUT many women have spent a lifetime caring and may experience burnout (Takai, et. al., 2011), which could reduce their reported compassion levels.

11. **Ali. L., Hedman, B., Krevers, B., Sjostrom, N and Skarsater, I. "Support for young informal carers of persons with mental illness: A mixed methods study." Issues in Mental Health, 34:611-618**

Young informal carers are in a sensitive developing phase and experiencing changes in world view and experiences and often take on tasks with a greater responsibility level than their years (Becker, 2007). This group want professionals to value and respect their knowledge and take into account already established routines and ways of caring (Butler and Astbury, 2005; Grant et al., 2008).

Young carers reported the need to talk to someone who could help them tolerate their situation and many did not know where to go for support and lacked professional support in developing strategies or techniques.

Many young people did turn to family and friends but were careful not to overload them so as tom maintain this social/familial network.
They also believed that web support, counselling, group counselling and supportive information would improve their situation although only a few had actually used any of these.

Once cases are considered closed by professional, sign off means no further support for the carer (Ewertson, wt. al., 2011, 2012).

Young carers describe school friends as people they can turn to but that they don't want to show vulnerability. Isolation, stigma and school difficulties faced by this group are well documented (Butler and Astbury, 2005; Ostman and Kjellin, 2002). About half felt they were alone in their situation.

The person cared for is often extremely close and important and suggestions that they turn their back on them to look after themselves is hurtful (Ali, et al., 2012) and compromised their sense of identity (Earley et al, 2007).

12. Lloyd, K. "Happiness and Wellbeing of carers: Extent, nature and correlates of caring among 10 and 11 yesr old school children." Journal of Happiness Studies (2013) 14:67-80

>4000 10/11 year olds
Report poorer self-reported health, wellbeing and happiness with life overall.. Children who are carers experience more bullying and are less happy at school, tend to have poorer educational outcomes when compared with children who are not carers.
Carers were more likely to report feelings of sadness, loneliness, not having enough time for themselves and not being able to do things they want in their free time.

Sahoo and Suar (2010) – Children who are carers can experience negative feelings such as insecurity, , distrust and worry but also teaches children positive values including nurturance, endurance and sympathy.

Becker (2007) – Caring responsibilities significantly restrict their development, participation and opportunities and educational attainment.

13. McAndrew, S. Warne, T, Fallon, D and Moran, P. "Young, Gifted and Caring: A project narrative of young carers, their mental health and getting them involved in education research and practice." International Journal of Mental Health Nursing (2012) 21, 12-19

Following key messages emerged:

- Organisations need to listen and engage with young carers
- Young carers need practical and emotional support
- Young carers need a safe place where they can relax and be listened to
- Young carers need to be at the centre of conversations that affect them
- Schools need to be flexible in order to accommodate young carers
- Young cares are best placed to educate the educators in terms of experience and recognition of other young carers
- Actions speak louder than words

14. **Wingham, J., Frost, J., and Britten, N. "Behind the smile: qualitative study of caregivers' anguish and management responses while caring for someone living with heart failure." BMJ Open 2017;7:e014126. doi: 10.1136/bmjopen-2016-014126**

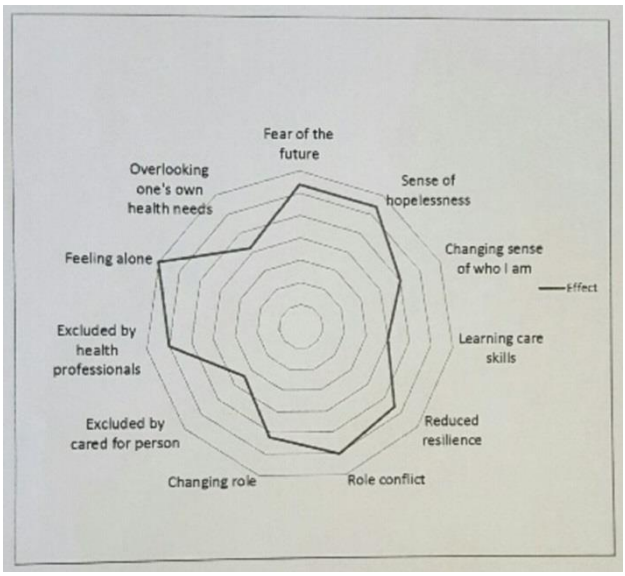
Qualitative research – 22 interviews from 3 centres across the UK

This paper cites the physical issues for caregivers:

- The majority of caregivers have health and well-being problems of their own, either pre-existing or arising from the burden of their caregiving activities
- The objective burden is due to activities that include physical tasks such as washing, dressing, feeding and assistance with mobility, sometimes also performed at night

Interviewees reported:

- They often put the health of the cared-for person before their own and frequently delayed going to the general practitioner (GP) until they themselves were in crisis. There were examples of delaying hip replacement surgery, unreported chest pain or mental health problems. This was more likely to occur when the cared-for person was severely affected by heart failure or other conditions or when there was a lack of a supportive social network.
- Overall, the dimensions identified as affecting care-givers were as seen in the diagram below, of which one is: overlooking one's own health needs:



15. **Davies F, Edwards A, Brain K, et al "'You are just left to get on with it': qualitative study of patient and carer experiences of the transition to secondary progressive multiple sclerosis."**
BMJ Open 2015;5:e007674. doi: 10.1136/bmjopen-2015-007674

Qualitative research interviewing and focus groups – 33 people

In general:

- Carers were less likely to use health professionals as part of their own support network
- They valued the health professionals for how they could support the cared for person, and often if the cared for person was adequately supported this had a positive impact on carers.
- Carers had rarely been offered support for themselves and several commented on the fact the research interview was their first ever opportunity to formally discuss their caring responsibilities.

16. **Shu, C.-C., Cumming, R. G., Kendig, H. L., Blyth, F. M., Waite, L. M., Le Couteur, D. G., Handelsman, D. J. and Naganathan, V. (2017), Health status, health behaviours and anxiety symptoms of older male caregivers: Findings from the Concord Health and Ageing in Men Project. Australasian Journal on Ageing, 36: 151–157. doi:10.1111/ajag.12376**

Australian study, self-completed questionnaires and face-to-face interviews with 1705 community living men aged ≥70.

Older male caregivers did not have worse physical health or more depressive symptoms than non-caregivers, but being a caregiver was associated with increased likelihood of reporting anxiety symptoms. Caregivers had similar levels and frequencies of leisure activities but did more housework activities than non-caregivers.

Appendix 2 Carer's Assessment Of Difficulties Index (CADI)

Below are some statements which carers have made about the difficulties they face. Please read each statement and show if it applies to you by circling the appropriate number in Column A.
For each statement which sometimes or always applies to you, please show how stressful you find it by circling the appropriate number in Column B.

Ratings
Column A
This statement
☐☐Never applies to me - 1
☐☐Sometimes applies to me - 2
☐☐Always applies to me - 3

Column B
I Find this aspect of caring
☐☐Not stressful - 1
☐☐Moderately stressful - 2
☐☐Very stressful - 3

1. I don't have enough private time for myself.

2. I sometimes feel helpless/not in control of the situation.

3. I can't devote enough time to other family members.

4. It causes financial difficulties.

5. The person I care for sometimes manipulates me.

6. The person I care for is immobile/has problems in getting around.

7. Professional workers don't seem to appreciate the problems carers face.

8. It restricts your social life/outside interest.

9. It can put a strain on family relationships.

10. It is physically tiring.

11. The person I care for can demand too much of me.

12. I no longer have a meaningful relationship with the person I care for.

13. The person I care for needs a lot of help with personal care.

14. The person I care for doesn't always help as much as they could.

15. My sleep is affected.

16. Relatives don't keep in touch as often as I'd like.

17. I feel angry about the situation.

18. I can't see friends as often as I'd like.

19. My emotional well-being suffers.

20. I can't have a break or take a holiday.

21. My standard of living has fallen.

22. The person I care for doesn't always appreciate what I do.

23. My physical health has suffered.

24. The person I care for is incontinent.

25. The behaviour of the person I care for is a problem.

26. There is no satisfaction to be gained from caring.

27. I don't get enough help from the health and social services.

28. Some family members don't help as much as they could.

29. I can't relax because of worry about caring.

30. I feel guilty about the situation.

Appendix 3. Quantitative data

Chart A3.1 Count of unpaid carers within each ERY ward. 1+ hours per week. Census 2011. Source: PHE Local Health

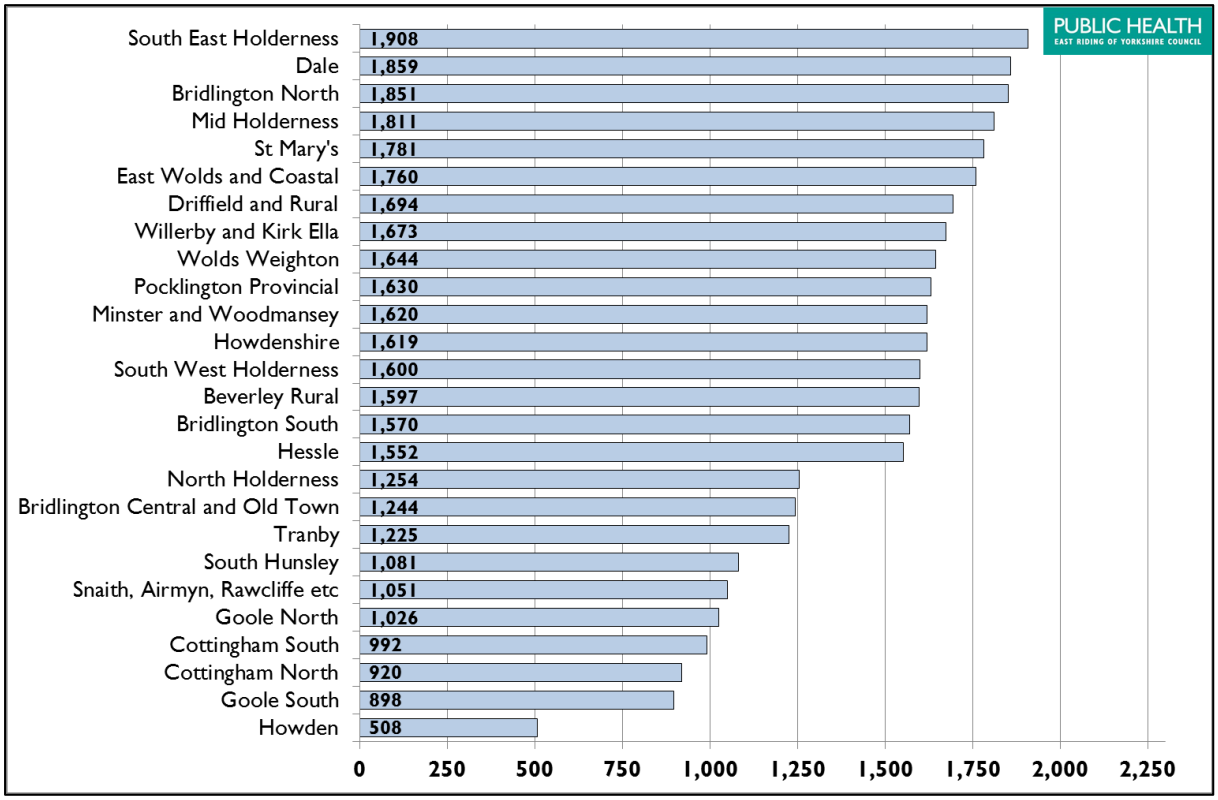


Chart A3.2 Number of unpaid carers as % of total ward population (all ages). One hour or more unpaid care per week, 2011. ERY wards compared to ERY average. Source: PHE Local Health

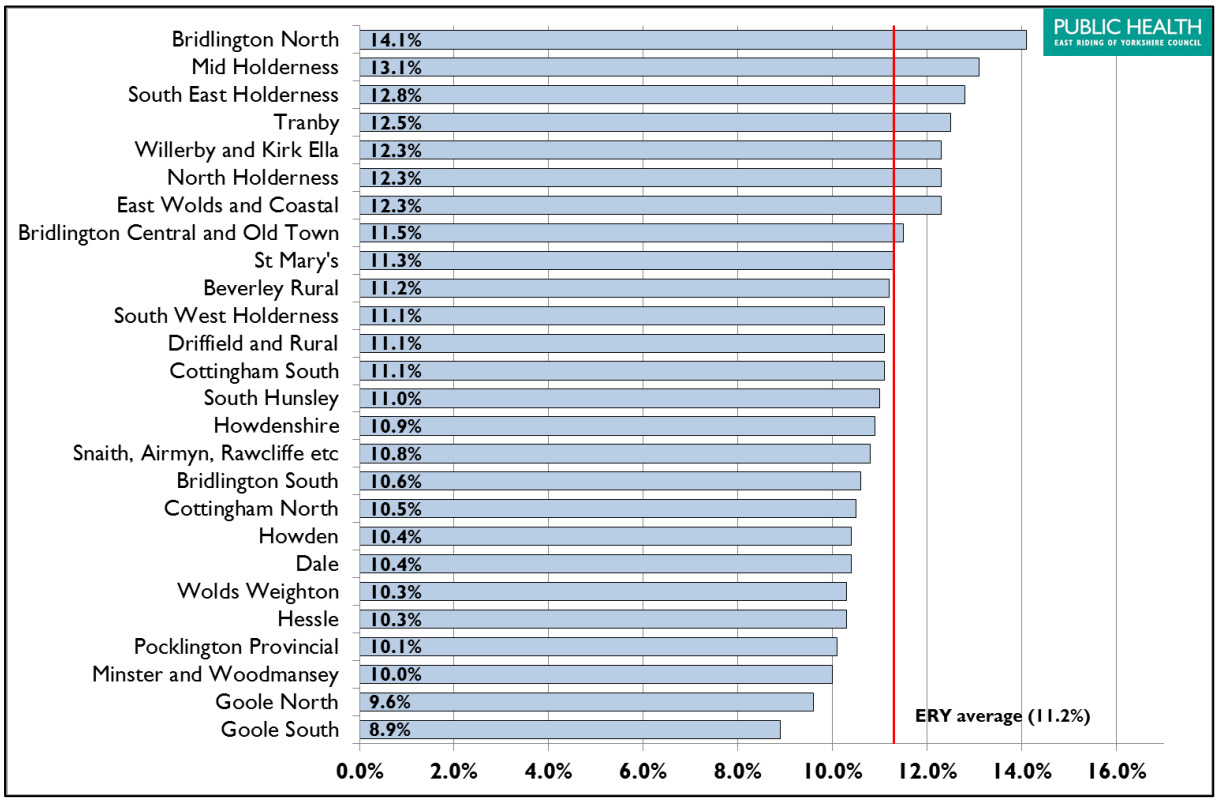


Table A3.3 Number of carers by ward providing 1+ hours and 50+ hours of unpaid care. Tables are sorted in descending order by number of carers. 2011. Source: PHE Local Health and ERY Carers Support Service and

Ward Name	Number of carers: 1 hour or more per week (2011 Census)	Ward Name	Number of carers: 50 hours or more per week (2011 Census)	Number registered with ERY Carers Support Service (May 2017) [hours of care not specified]	Difference between census 50hrs+ & ERY Carers Support
South East Holderness	1,908	South East Holderness	578	194	384
Dale	1,859	Bridlington North	548	170	378
Bridlington North	1,851	Bridlington South	522	169	353
Mid Holderness	1,811	Mid Holderness	448	113	335
St Mary's	1,781	East Wolds and Coastal	413	137	276
East Wolds and Coastal	1,760	Bridlington Central and Old Town	410	139	271
Driffield and Rural	1,694	South West Holderness	402	139	263
Willerby and Kirk Ella	1,673	Driffield and Rural	379	143	236
Wolds Weighton	1,644	Minster and Woodmansey	355	169	186
Pocklington Provincial	1,630	Howdenshire	341	135	206
Minster and Woodmansey	1,620	North Holderness	340	108	232
Howdenshire	1,619	St Mary's	328	192	136
South West Holderness	1,600	Hessle	325	105	220
Beverley Rural	1,597	Dale	321	112	209
Bridlington South	1,570	Wolds Weighton	311	119	192
Hessle	1,552	Willerby and Kirk Ella	304	110	194
North Holderness	1,254	Beverley Rural	297	135	162
Bridlington Central and Old Town	1,244	Goole North	283	99	184
Tranby	1,225	Pocklington Provincial	273	125	148
South Hunsley	1,081	Tranby	273	81	192
Snaith, Airmyn, Rawcliffe & Marshland	1,051	Snaith, Airmyn, Rawcliffe & Marshland	253	68	185
Goole North	1,026	Goole South	251	97	154
Cottingham South	992	Cottingham South	201	68	133
Cottingham North	920	South Hunsley	176	61	115
Goole South	898	Cottingham North	164	76	88
Howden	508	Howden	99	47	52

East Riding of Yorkshire UA	37,368	East Riding of Yorkshire UA	8,595
England	5,430,016	England	1,256,237

Table A3.4 ERY wards, number of people (all ages) providing unpaid care. Number of hours per week, by number and percent. 2011. Source NOMIS

Ward	Population	Provides 1 hour or more unpaid care a week	Provides 1 to 19 hours unpaid care a week	Provides 20 to 49 hours unpaid care a week	Provides 50 or more hours unpaid care a week	Provides 1 hour or more unpaid care a week	Provides 1 to 19 hours unpaid care a week	Provides 20 to 49 hours unpaid care a week	Provides 50 or more hours unpaid care a week
Beverley Rural	14,320	1,597	1,142	158	297	11.2%	8.0%	1.1%	2.1%
Bridlington Central and Old Town	10,849	1,244	634	200	410	11.5%	5.8%	1.8%	3.8%
Bridlington North	13,166	1,851	1,038	265	548	14.1%	7.9%	2.0%	4.2%
Bridlington South	14,784	1,570	777	271	522	10.6%	5.3%	1.8%	3.5%
Cottingham North	8,730	920	669	87	164	10.5%	7.7%	1.0%	1.9%
Cottingham South	8,919	992	694	97	201	11.1%	7.8%	1.1%	2.3%
Dale	17,874	1,859	1,381	157	321	10.4%	7.7%	0.9%	1.8%
Driffield and Rural	15,199	1,694	1,053	262	379	11.1%	6.9%	1.7%	2.5%
East Wolds and Coastal	14,334	1,760	1,142	205	413	12.3%	8.0%	1.4%	2.9%
Goole North	10,711	1,026	622	121	283	9.6%	5.8%	1.1%	2.6%
Goole South	10,099	898	508	139	251	8.9%	5.0%	1.4%	2.5%
Hessle	15,000	1,552	1,052	175	325	10.3%	7.0%	1.2%	2.2%
Howden	4,865	508	336	73	99	10.4%	6.9%	1.5%	2.0%
Howdenshire	14,888	1,619	1,097	181	341	10.9%	7.4%	1.2%	2.3%
Mid Holderness	13,836	1,811	1,146	217	448	13.1%	8.3%	1.6%	3.2%
Minster and Woodmansey	16,240	1,620	1,081	184	355	10.0%	6.7%	1.1%	2.2%
North Holderness	10,158	1,254	740	174	340	12.3%	7.3%	1.7%	3.3%
Pocklington Provincial	16,102	1,630	1,199	158	273	10.1%	7.4%	1.0%	1.7%
Snaith, Airmyn, Rawcliffe and Marshland	9,725	1,051	672	126	253	10.8%	6.9%	1.3%	2.6%
South East Holderness	14,893	1,908	1,083	247	578	12.8%	7.3%	1.7%	3.9%
South Hunsley	9,871	1,081	825	80	176	11.0%	8.4%	0.8%	1.8%
South West Holderness	14,473	1,600	988	210	402	11.1%	6.8%	1.5%	2.8%
St Mary's	15,828	1,781	1,266	187	328	11.3%	8.0%	1.2%	2.1%
Tranby	9,794	1,225	821	131	273	12.5%	8.4%	1.3%	2.8%
Willerby and Kirk Ella	13,578	1,673	1,213	156	304	12.3%	8.9%	1.1%	2.2%
Wolds Weighton	15,943	1,644	1,176	157	311	10.3%	7.4%	1.0%	2.0%
East Riding of Yorkshire LA	334,179	37,368	24,355	4,418	8,595	11.2%	7.3%	1.3%	2.6%

Map A3.5 ERY wards (grouped into old locality areas, previously used extensively in JSNA & CCG work). Source: East Riding of Yorkshire Data Observatory

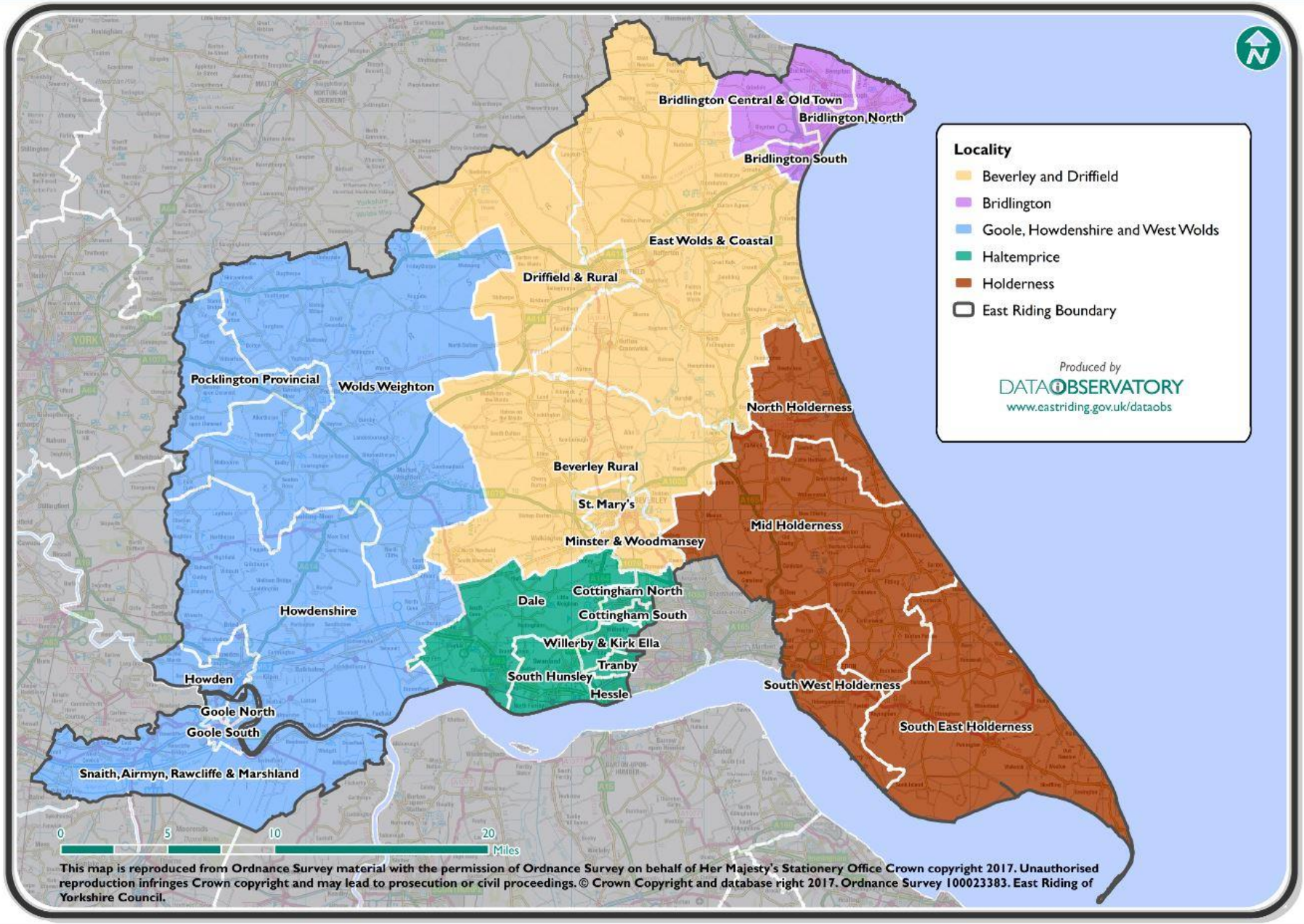


Chart A3.6 Percent of unpaid carers (all ages) living with local deprivation quintile areas (IMD 2015), based on ERY LSOA scores. Undertaking 1+ and 50+ hours unpaid care per week, 2011. Source: NOMIS

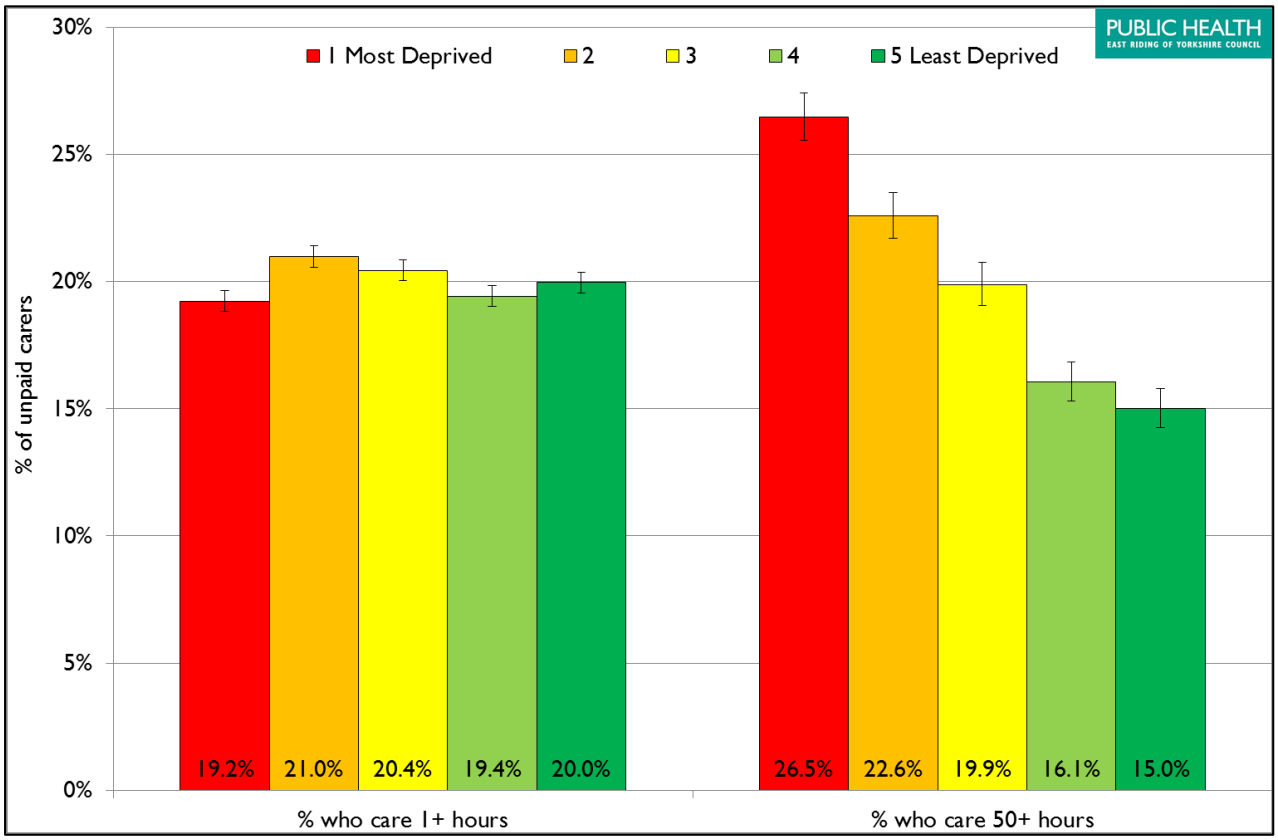


Table A3.7 Unpaid carers (1+ hours per week) by gender and age group. Each percentage represents the category as a percent of the total carer population, 2011. ERY compared to England, 2011. Source: NOMIS*

	ERY					England				
Gender	**Overall**	**0-24**	**25-49**	**50-64**	**65+**	**Overall**	**0-24**	**25-49**	**50-64**	**65+**
Males	42%	3%	10%	16%	13%	42%	3%	14%	15%	11%
Females	58%	3%	18%	24%	13%	58%	4%	21%	21%	11%
Total	**100%**	**5%**	**28%**	**41%**	**26%**	**100%**	**7%**	**35%**	**36%**	**22%**

Table A3.8 Unpaid carers (50+ hours per week) by gender and age group. Each percentage represents the category as a percent of the total carer population, 2011. ERY compared to England, 2011. Source: NOMIS*

	ERY					England				
Gender	**Overall**	**0-24**	**25-49**	**50-64**	**65+**	**Overall**	**0-24**	**25-49**	**50-64**	**65+**
Males	42%	1%	8%	12%	21%	40%	1%	10%	11%	17%
Females	58%	1%	16%	18%	23%	60%	2%	22%	17%	19%
Total	**100%**	**2%**	**23%**	**30%**	**44%**	**100%**	**4%**	**32%**	**28%**	**36%**

** Please note that the percentages have been rounded. May not show in all age groups ERY that females represent a larger proportion than males.*

Chart A3.9 Percent of unpaid carers (1 hour + per week) by ethnicity, 2011. ERY compared to England and CIPFA neighbours, 2011. Caution: Y axis does not start at "0". Source: NOMIS

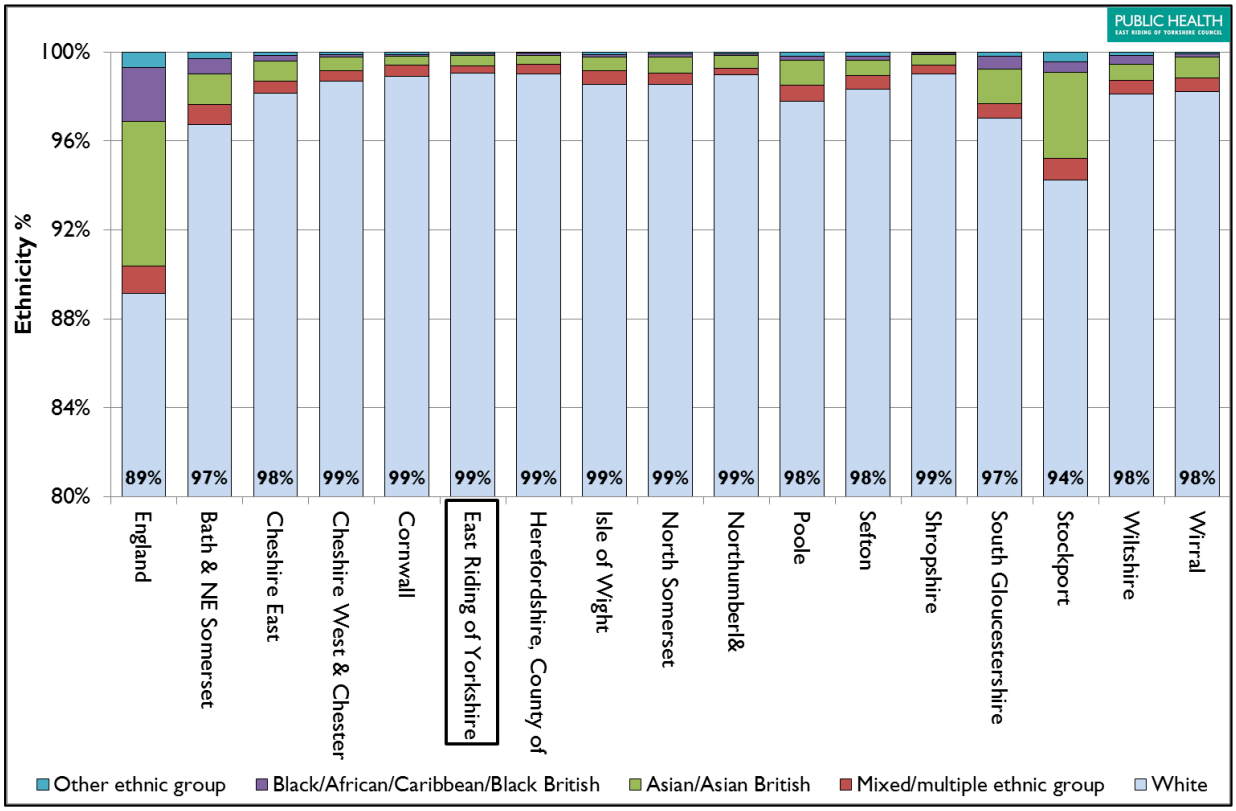


Chart A3.10 Percent of unpaid carers (1+ hours) who are economically inactive. ERY wards, 2011. Source: NOMIS

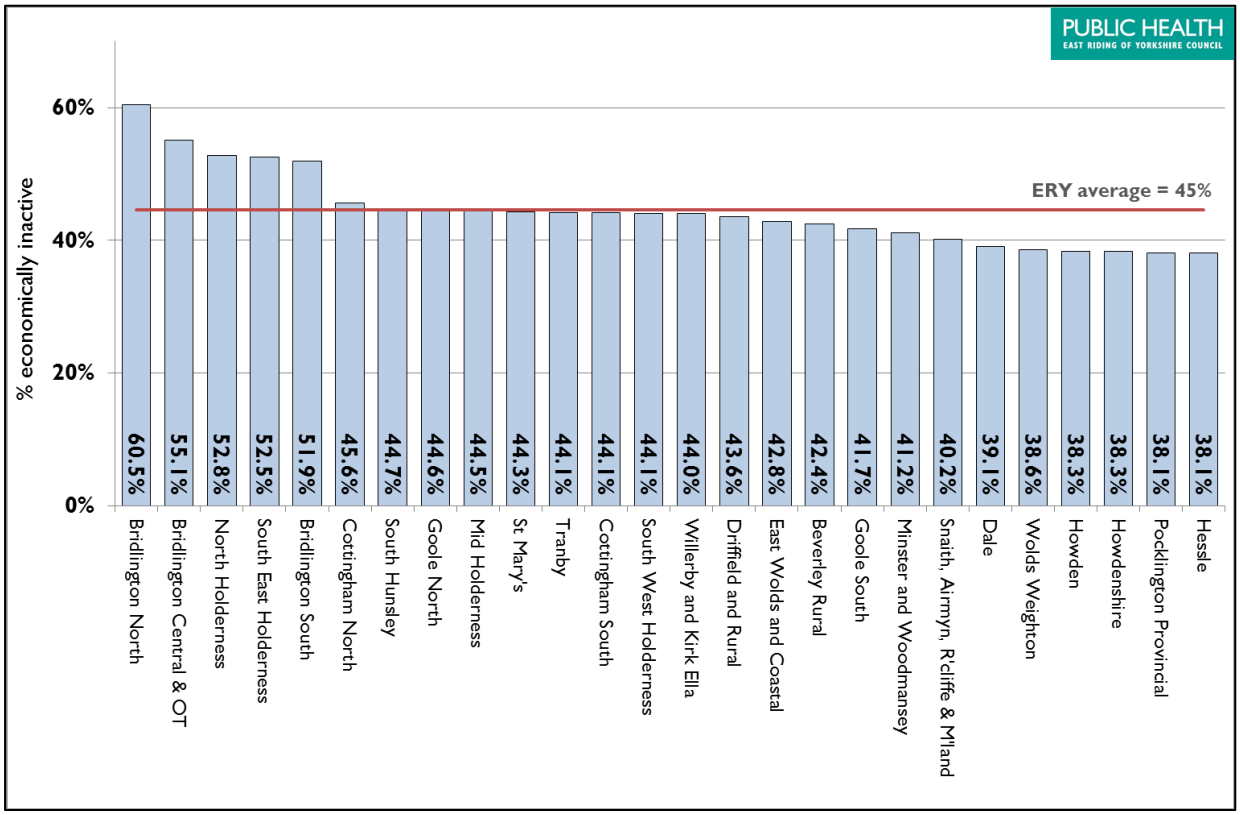


Chart A3.11 Percent of unpaid carers (50+ hours) who are economically inactive. ERY wards, 2011. Source: NOMIS

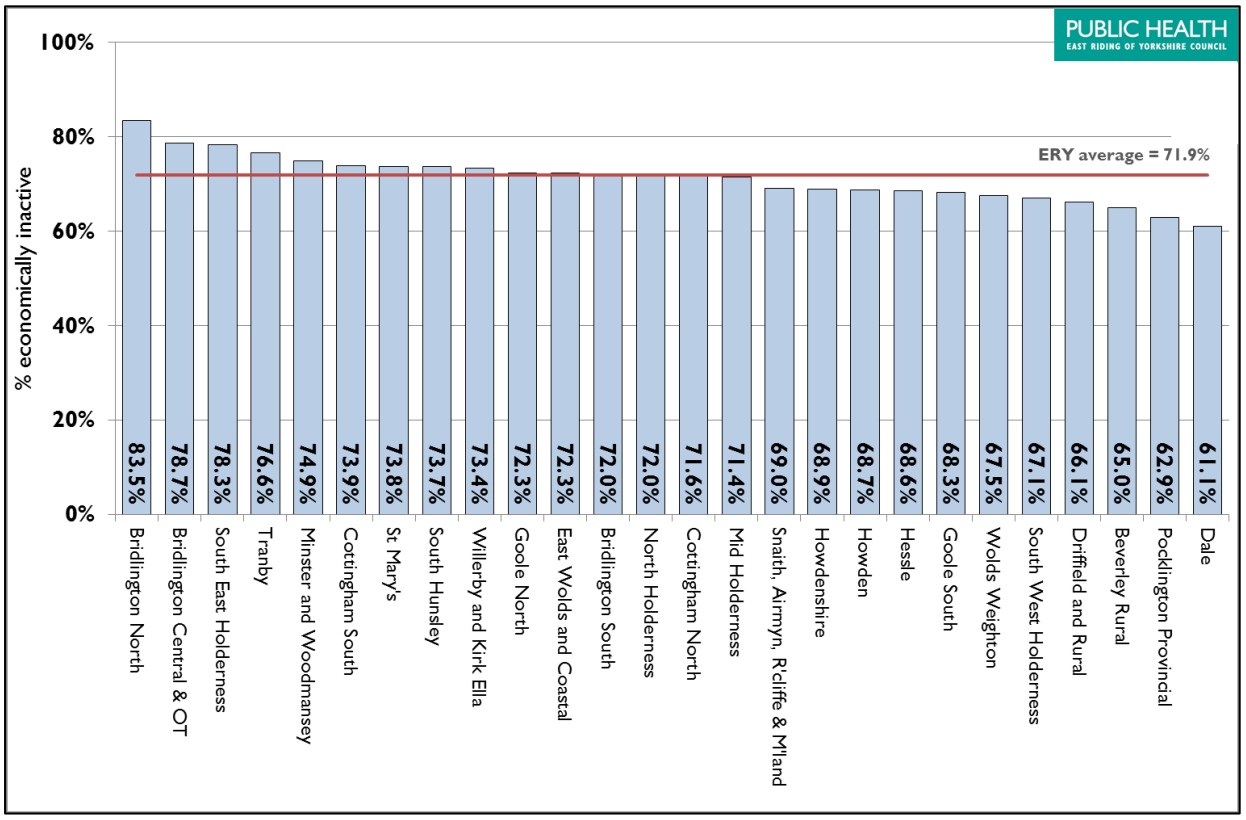


Chart A3.12 Unpaid carers for 1 hour or more: age bands as percent of total unpaid carers, ERY compared to England. 2011 Census. Source: NOMIS

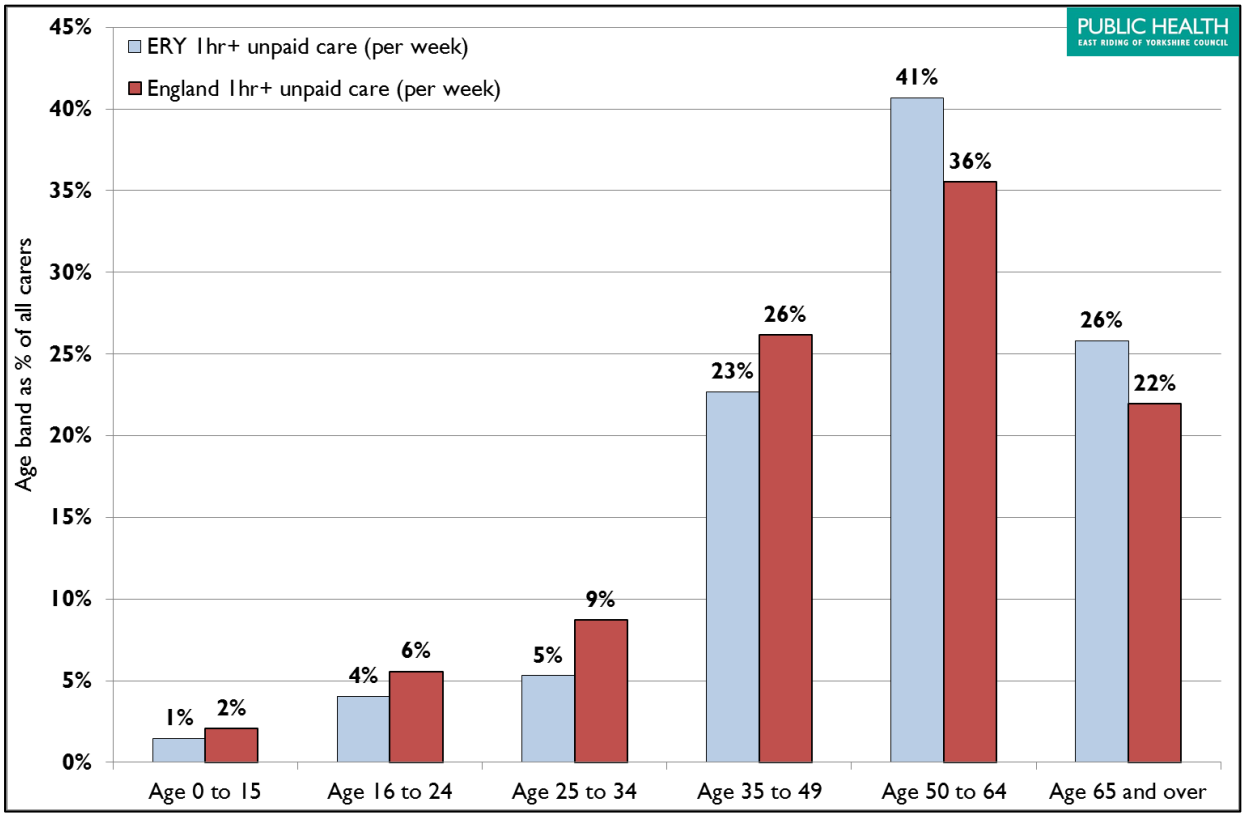


Chart A3.13 Unpaid carers for 50 hours or more: age bands as percent of total unpaid carers, ERY compared to England. 2011 Census. Source: NOMIS

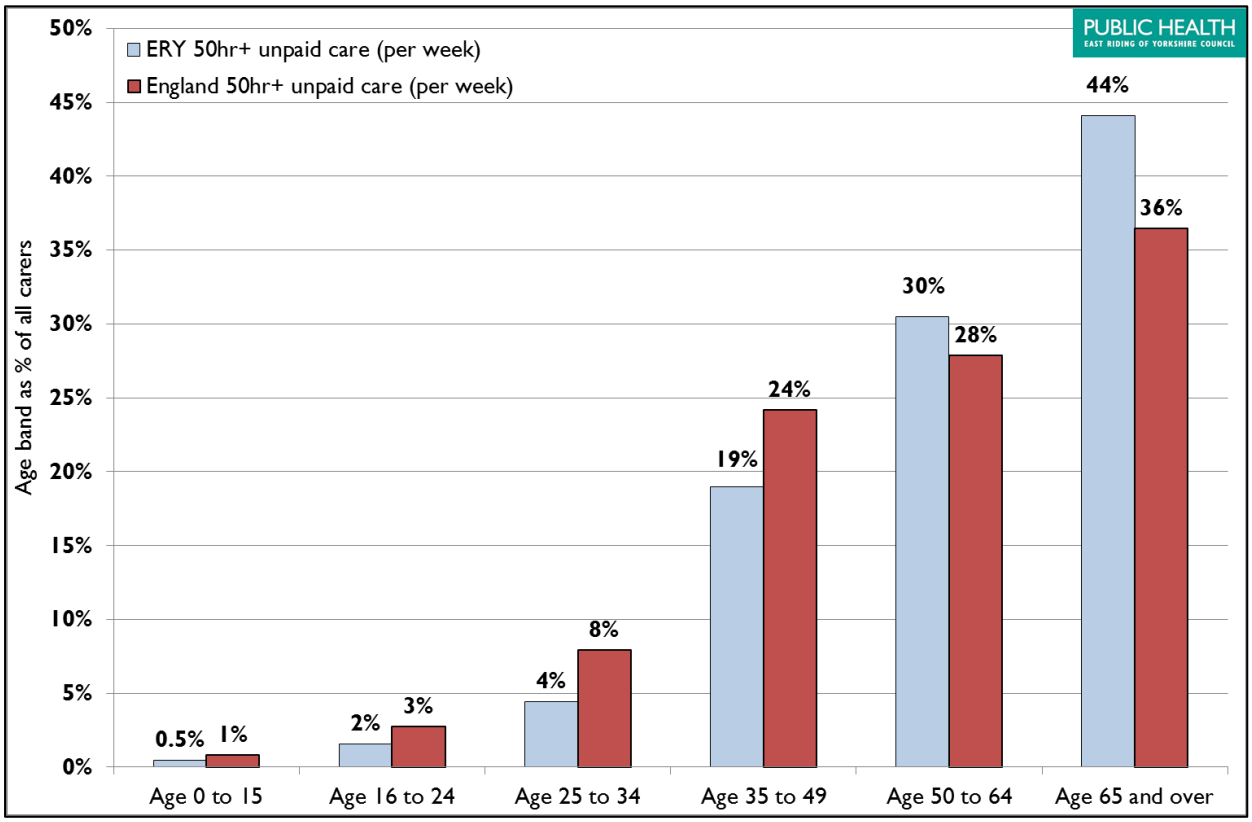


Table A3.15 Unpaid carers aged 65+ years. Count of carers & crude rate per 1,000 population aged 65+ in each ward. Source: ERY Carers Support Service (for numerator data)

Ward Name	Count of 65+ year olds	ONS Mid-2015 estimate 65+ year olds	Rate of carers aged 65+ per 1,000 ward population aged 65+
St Mary's	103	3,989	26
Minster and Woodmansey	78	3,217	24
South East Holderness	81	3,970	20
Beverley Rural	64	3,396	19
Bridlington North	107	5,507	19
Driffield and Rural	71	3,742	19
Howden	21	1,128	19
Bridlington South	65	3,536	18
Goole South	28	1,587	18
Willerby and Kirk Ella	68	3,862	18
Bridlington Central and Old Town	48	2,789	17
Goole North	40	2,311	17
Mid Holderness	57	3,424	17
South West Holderness	63	3,729	17
Cottingham North	35	2,193	16
Hessle	49	2,992	16
Howdenshire	53	3,248	16
North Holderness	51	3,104	16
Snaith, Airmyn, Rawcliffe and Marshland	33	2,128	16
Wolds Weighton	55	3,430	16
Dale	53	3,605	15
East Wolds and Coastal	60	3,925	15
Pocklington Provincial	61	4,086	15
South Hunsley	35	2,606	13
Cottingham South	30	2,544	12
Tranby	23	2,548	9
Total (ERY)	1432	82,596	17

Chart A3.16 Unpaid Carers aged 65+ year olds projected increase from 2015. ERY compared to England and CIPFA neighbours. Source: POPPI

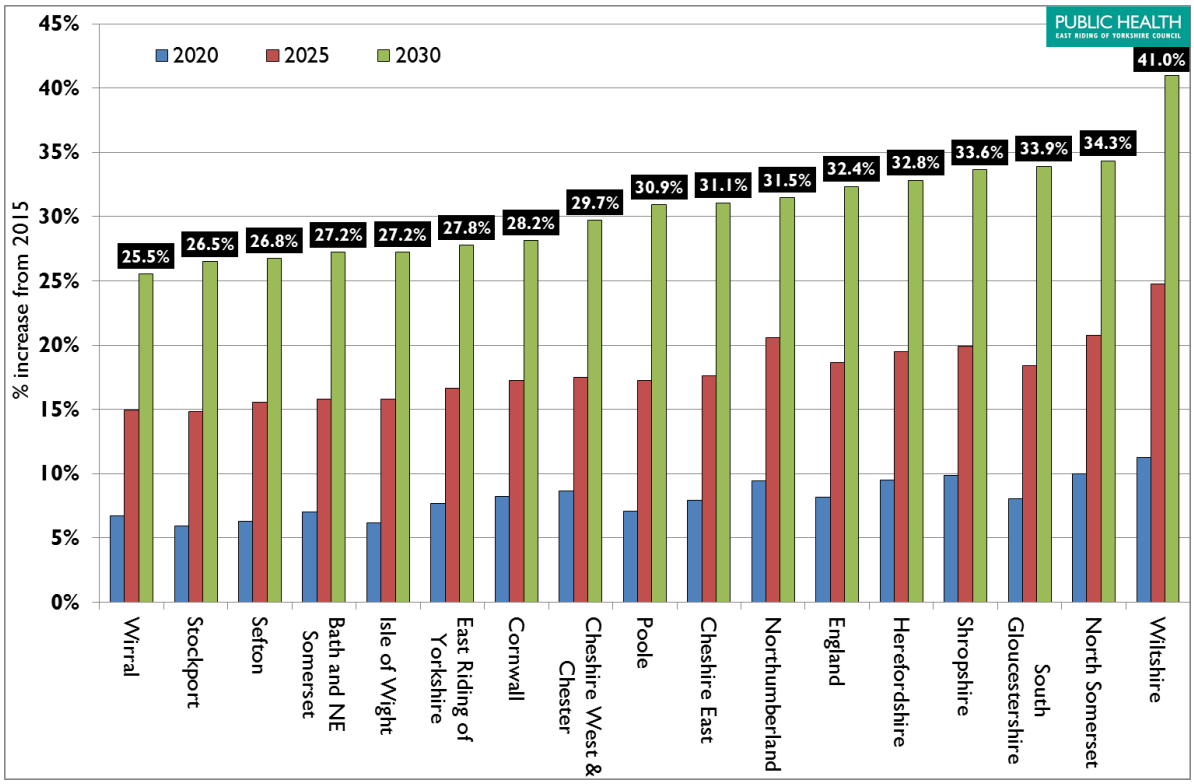


Table A3.17 SACE survey 2016/17, age group of 'cared for' person. Source: SACE survey

Age Group	Count of cared for persons by age group	Age group as % of all cared for persons in sample
18-24	22	4%
25-34	15	3%
35-49	51	9%
50-64	100	18%
65+	357	66%
Total	545	100%

80+*	164	30%
90+*	53	10%
Withheld	37	

** note the number of 90+ years cared for persons are also included within the 80+ years category*

- Median average age of cared for person: 72
- Mean average age of cared for person: 68
- Mode average age of cared for person: 72

Table A3.18 Age group of carer and the age group of the person they care for, in 5 year age bands (darker purple = higher percentage). For example, 36% of carers aged 75-79 look after persons who are also aged 75-79. August 2017. Source: ERY Carers Support Service

		Age band of cared for person																		
		15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85-89	90-94	95-99	100-104	105+	Total
Age band of carer	15-19	0%	0%	0%	0%	0%	0%	0%	33%	0%	67%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
	20-24	0%	5%	0%	10%	0%	10%	19%	24%	5%	14%	5%	10%	0%	0%	0%	0%	0%	0%	0%	100%
	25-29	0%	7%	15%	11%	7%	4%	7%	22%	19%	0%	4%	0%	0%	0%	0%	4%	0%	0%	0%	100%
	30-34	0%	0%	6%	26%	9%	9%	9%	15%	6%	12%	3%	0%	0%	6%	0%	0%	0%	0%	0%	100%
	35-39	4%	0%	0%	16%	18%	13%	5%	2%	5%	9%	11%	9%	0%	4%	0%	2%	2%	0%	0%	100%
	40-44	8%	15%	1%	1%	6%	19%	13%	5%	2%	6%	1%	10%	2%	5%	5%	1%	0%	0%	0%	100%
	45-49	2%	12%	7%	1%	2%	5%	17%	13%	4%	3%	6%	4%	8%	9%	6%	1%	1%	0%	0%	100%
	50-54	3%	17%	8%	3%	1%	3%	6%	13%	9%	4%	1%	2%	10%	9%	8%	2%	1%	0%	0%	100%
	55-59	1%	6%	7%	4%	3%	1%	3%	9%	14%	8%	6%	2%	4%	11%	13%	6%	0%	0%	0%	100%
	60-64	0%	4%	4%	4%	5%	3%	2%	2%	9%	21%	11%	5%	4%	3%	10%	10%	1%	0%	0%	100%
	65-69	0%	1%	2%	3%	4%	7%	5%	2%	3%	13%	22%	17%	6%	2%	4%	5%	4%	0%	0%	100%
	70-74	0%	1%	1%	1%	3%	4%	5%	3%	2%	3%	10%	32%	18%	7%	2%	4%	3%	0%	0%	100%
	75-79	0%	0%	0%	0%	1%	2%	5%	4%	2%	2%	2%	12%	36%	25%	7%	2%	1%	0%	0%	100%
	80-84	0%	0%	0%	0%	0%	1%	1%	3%	2%	3%	1%	3%	15%	41%	21%	6%	1%	0%	0%	100%
	85-89	0%	0%	0%	0%	0%	0%	0%	1%	2%	2%	1%	2%	3%	17%	57%	14%	3%	0%	0%	100%
	90-94	0%	0%	0%	0%	0%	0%	0%	0%	0%	4%	0%	4%	0%	14%	50%	18%	11%	0%	0%	100%
	95-99	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	25%	50%	25%	0%	0%	100%

Table A3.19 Age group of carer and the age group of the person they care for, in 5 year age bands (darker purple = higher counts). August 2017. Source: ERY Carers Support Service

		Age band of cared for person																		
		15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85-89	90-94	95-99	100-104	105+	Total
Age band of carer	15-19	0	0	0	0	0	0	0	1	0	2	0	0	0	0	0	0	0	0	0	3
	20-24	0	1	0	2	0	2	4	5	1	3	1	2	0	0	0	0	0	0	0	21
	25-29	0	2	4	3	2	1	2	6	5	0	1	0	0	0	0	1	0	0	0	27
	30-34	0	0	2	9	3	3	3	5	2	4	1	0	0	2	0	0	0	0	0	34
	35-39	2	0	0	9	10	7	3	1	3	5	6	5	0	2	0	1	1	0	0	55
	40-44	7	13	1	1	5	16	11	4	2	5	1	9	2	4	4	1	0	0	0	86
	45-49	3	19	11	1	4	9	28	22	6	5	10	7	13	14	10	1	1	0	0	164
	50-54	10	51	24	8	4	10	17	41	27	13	4	7	29	26	23	7	3	0	0	304
	55-59	3	19	20	12	9	4	10	26	43	25	18	7	11	34	39	19	1	0	0	300
	60-64	0	15	15	15	17	10	6	8	32	71	39	18	13	12	33	34	5	0	0	343
	65-69	0	3	6	12	15	25	17	8	9	45	77	62	21	8	14	18	14	1	0	355
	70-74	0	2	4	5	13	14	18	13	7	13	41	126	72	27	8	16	11	1	1	392
	75-79	0	0	1	0	3	5	16	11	5	5	7	36	111	76	20	7	3	0	0	306
	80-84	0	0	0	0	1	2	3	6	4	8	3	8	37	98	51	15	2	1	0	239
	85-89	0	0	0	0	0	0	0	1	2	2	1	2	3	20	67	16	3	0	0	117
	90-94	0	0	0	0	0	0	0	0	0	1	0	1	0	4	14	5	3	0	0	28
	95-99	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	2	1	0	0	4
	Total	25	125	88	77	86	108	138	158	148	207	210	290	312	327	284	143	48	3	1	2778

Chart A3.22 ERY males. A comparison of "life expectancy at birth", against "healthy life expectancy at birth". Source: PHE

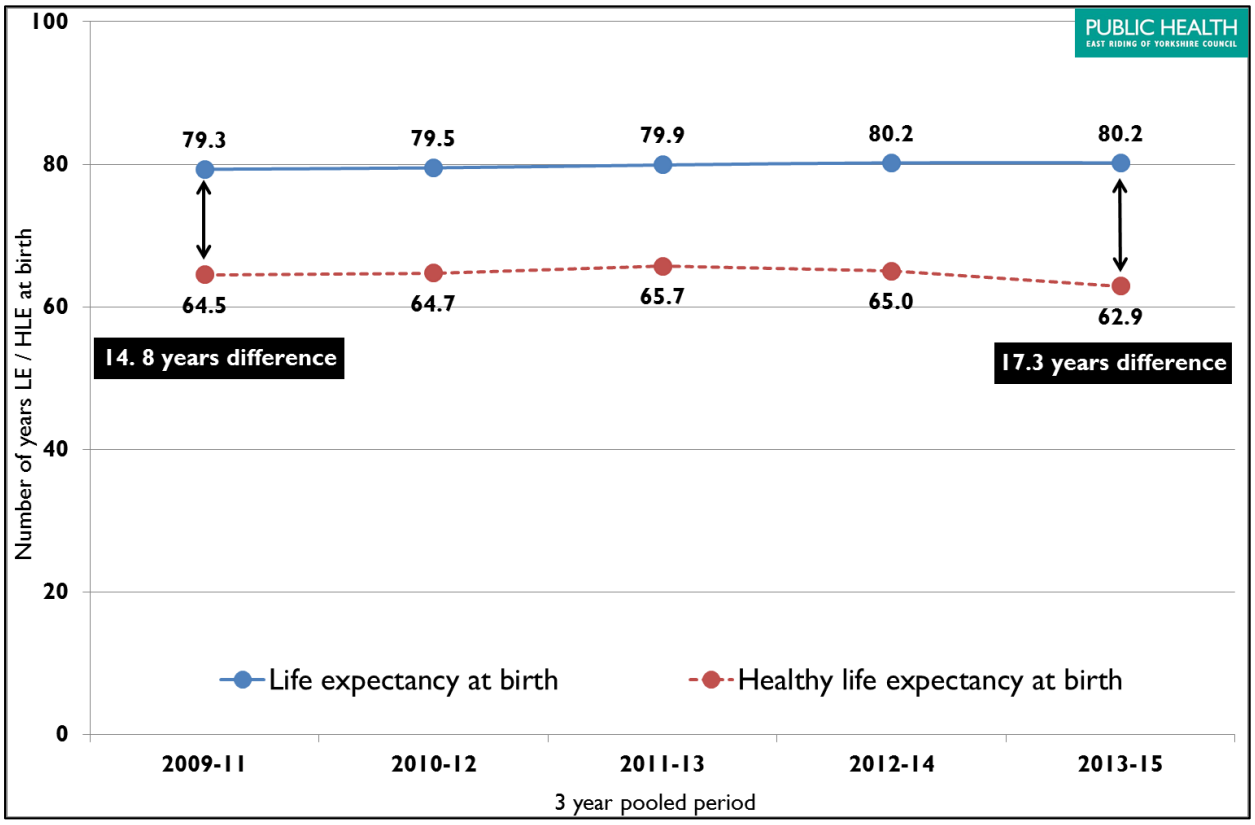


Chart A3.23 ERY females. A comparison of "life expectancy at birth", against "healthy life expectancy at birth". Source: PHE

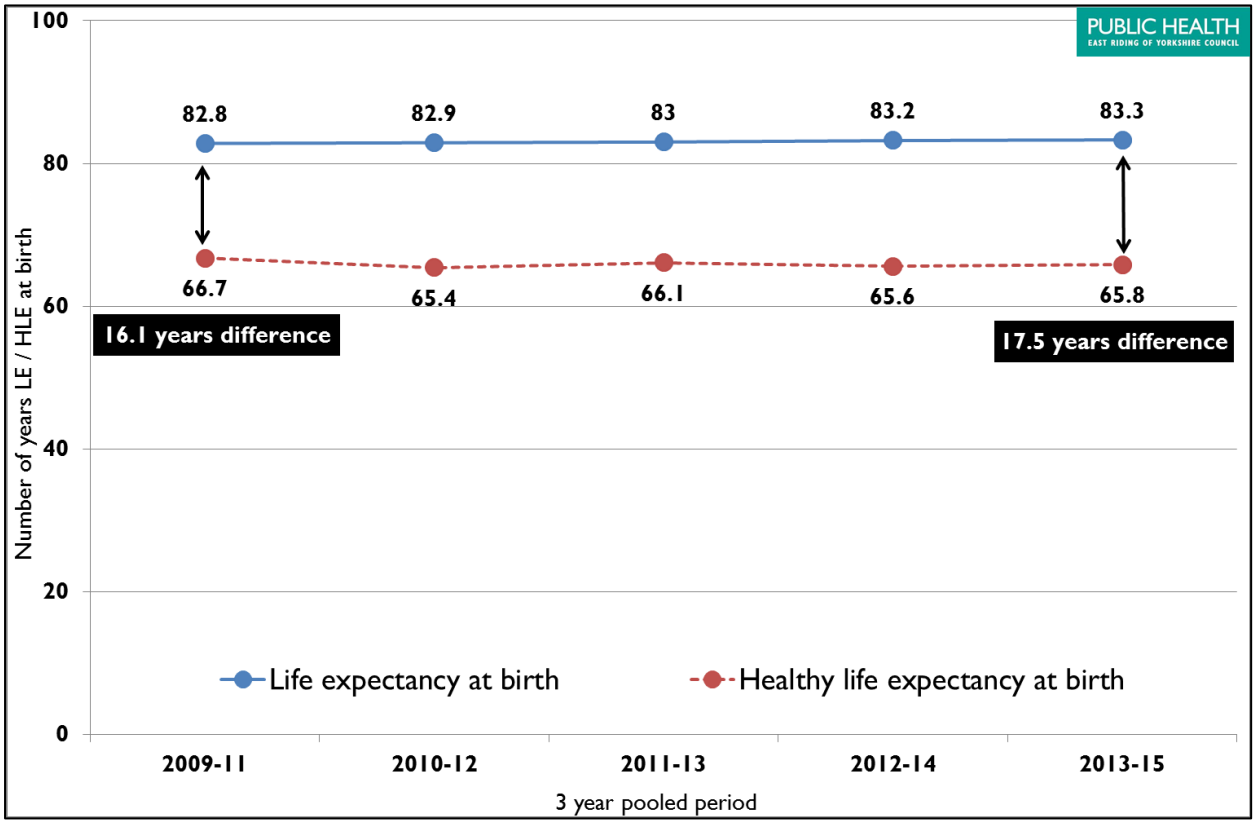


Chart A3.24 Percent of unpaid carers (1+ hours per week) who said their health was bad or very bad, 2011. ERY compared to England and CIPFA neighbours. Source: NOMIS

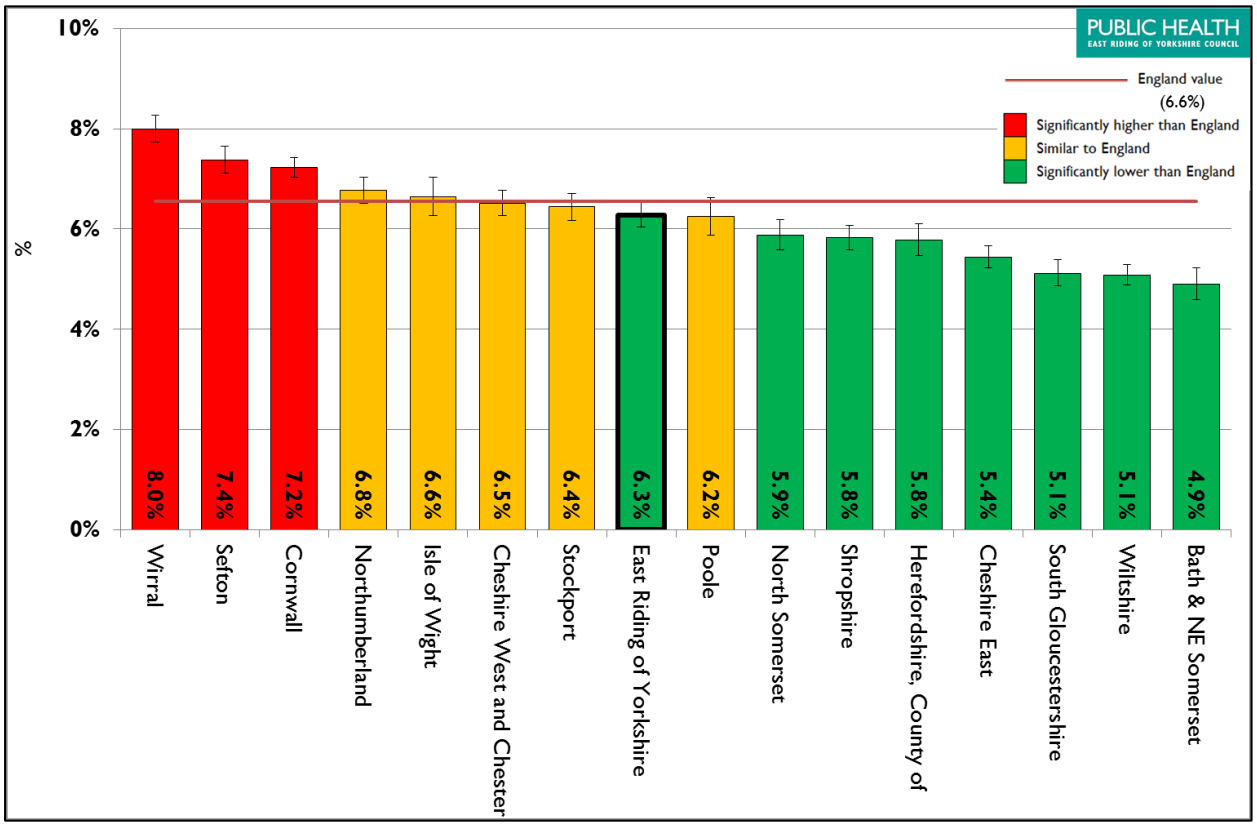


Chart A3.25 Percent of unpaid carers (50+ hours per week) who said their health was bad or very bad, 2011. ERY compared to England and CIPFA neighbours. Source: NOMIS

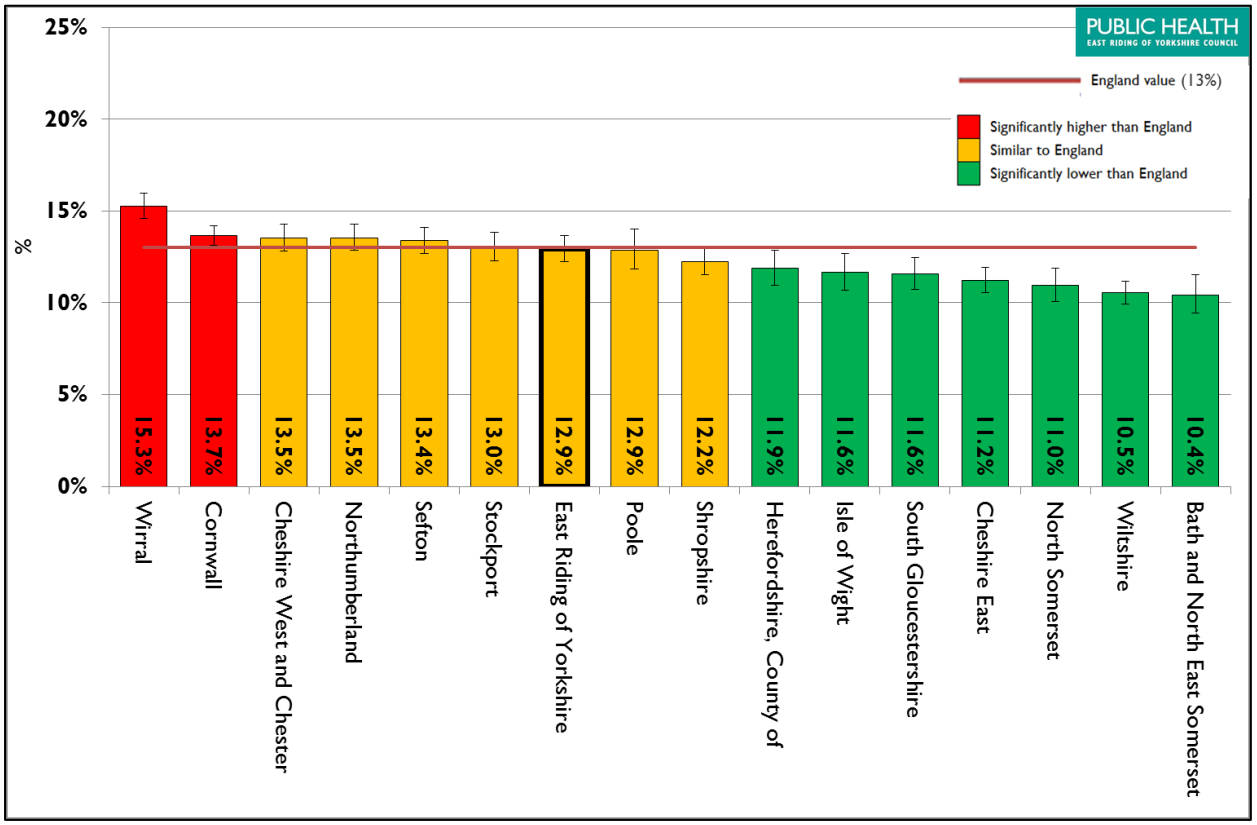


Chart A3.26 Percent of unpaid carers (1+ hours per week) who said their health was bad or very bad, 2011. ERY ward compared to ERY average. Actual count of carers with bad/very bad health is in brackets next to ward name Source: NOMIS

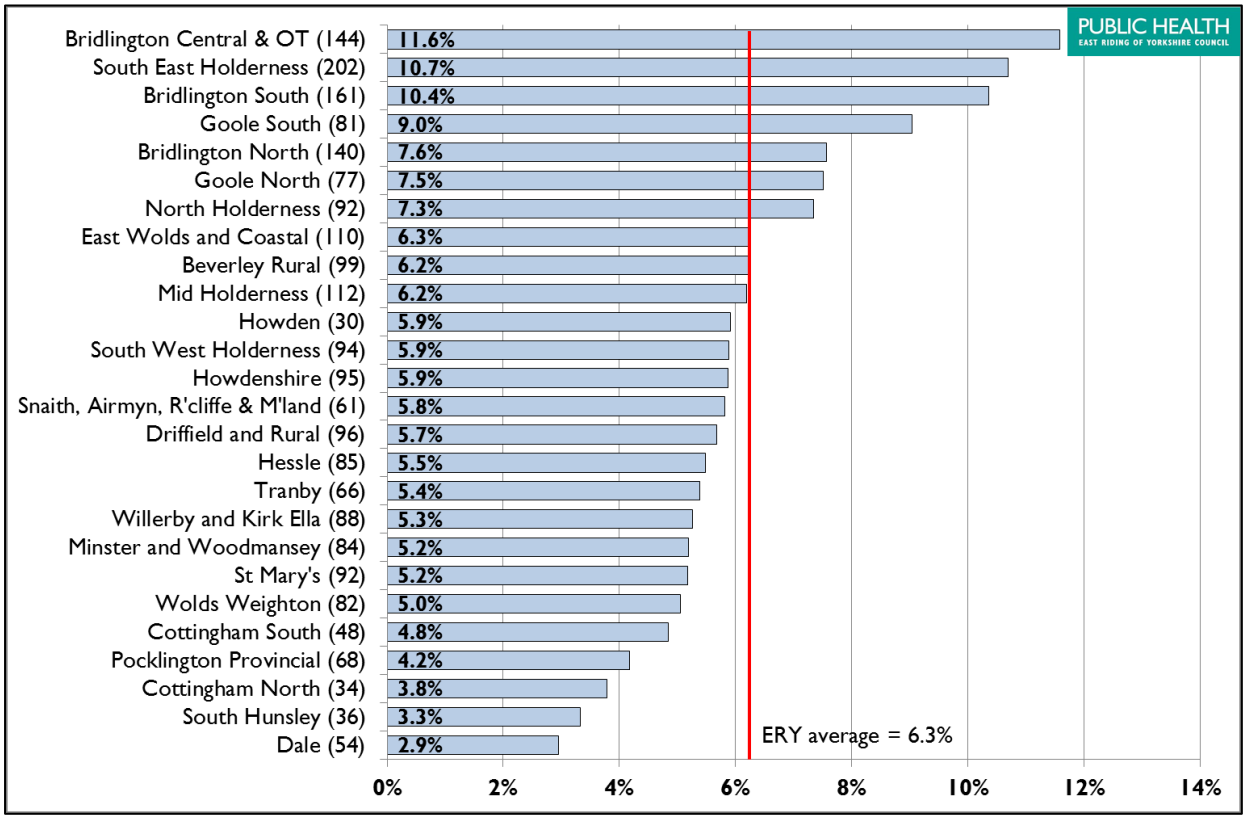


Chart A3.27 Percent of unpaid carers (1 hour + per week) who said their activities were limited a little or a lot, 2011. ERY compared to England and CIPFA neighbours. Source: NOMIS

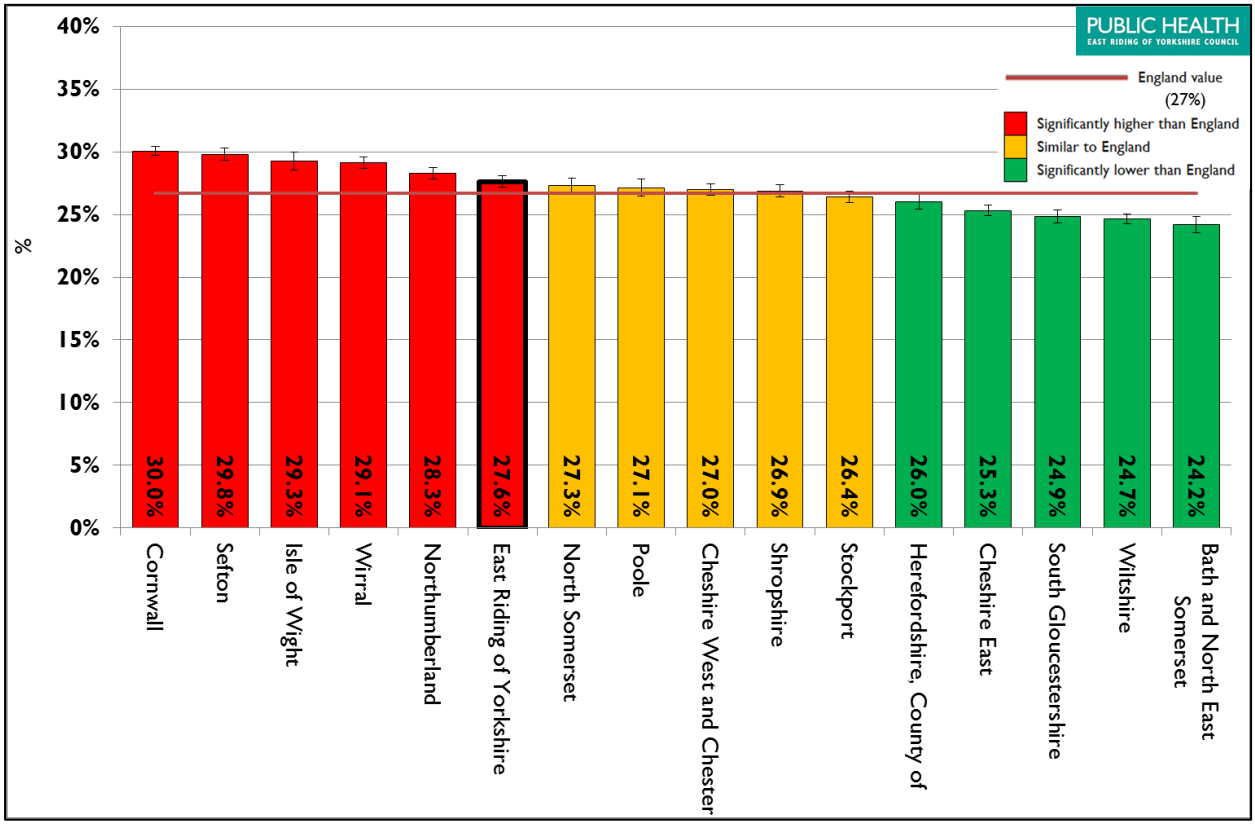


Chart A3.28 Percent of unpaid carers (50 hour + per week) who said their activities were limited a little or a lot, 2011. ERY compared to England and CIPFA neighbours. Source: NOMIS

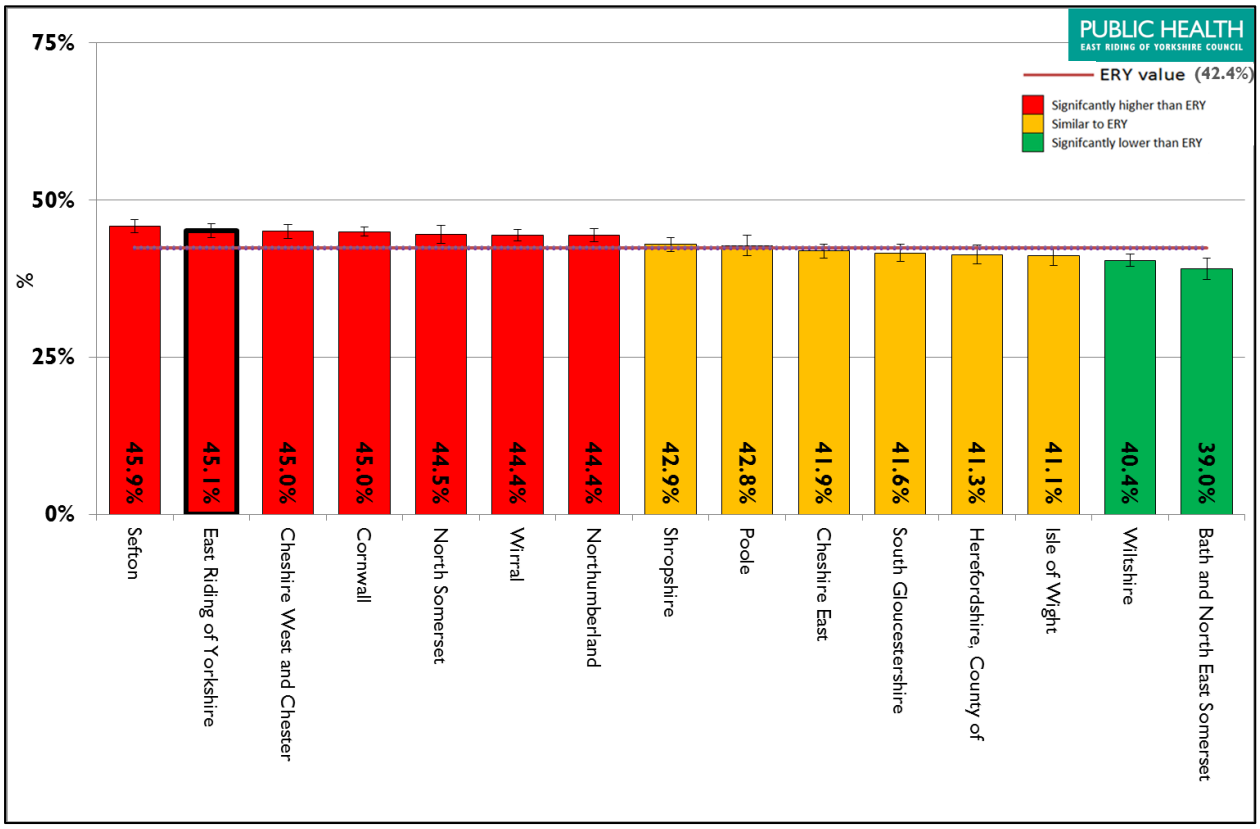


Table A3.29 ERY ward level counts and percentages for unpaid carers, 1+ hours and 50+ hours per week. 1) Health is bad or very bad 2) Day-to-day activities limited a little or a lot. Sorted alphabetically by ward name. Census 2011. Source: NOMIS

	Health is bad or very bad				Long-term health problem or disability: day-to-day activities limited a little or a lot			
Ward	**1+ hours (count)**	**1+ hours (%)**	**50+ hours (count)**	**50+ hours (%)**	**1+ hours (count)**	**1+ hours (%)**	**50+ hours (count)**	**50+ hours (%)**
Beverley Rural	99	6.2%	46	15.5%	398	25.1%	113	38.0%
Bridlington Central & OT	144	11.6%	74	18.1%	457	36.8%	198	48.4%
Bridlington North	140	7.6%	70	12.8%	655	35.4%	284	51.9%
Bridlington South	161	10.4%	91	17.6%	544	35.0%	242	46.7%
Cottingham North	34	3.8%	17	10.4%	250	27.8%	83	50.6%
Cottingham South	48	4.8%	24	11.9%	265	26.8%	99	49.3%
Dale	54	2.9%	23	7.3%	391	21.4%	123	38.9%
Driffield and Rural	96	5.7%	36	9.5%	463	27.4%	164	43.5%
East Wolds and Coastal	110	6.3%	53	12.8%	477	27.1%	182	44.1%
Goole North	77	7.5%	33	11.7%	328	32.0%	141	49.8%
Goole South	81	9.0%	36	14.4%	244	27.2%	101	40.4%
Hessle	85	5.5%	36	11.1%	351	22.6%	132	40.6%
Howden	30	5.9%	13	13.1%	133	26.2%	44	44.4%
Howdenshire	95	5.9%	32	9.4%	405	25.0%	130	38.1%
Mid Holderness	112	6.2%	59	13.2%	516	28.5%	198	44.2%
Minster and Woodmansey	84	5.2%	49	13.8%	414	25.6%	158	44.5%
North Holderness	92	7.3%	47	13.9%	420	33.5%	160	47.3%
Pocklington Provincial	68	4.2%	29	10.6%	379	23.3%	113	41.4%
Snaith, Airmyn, R'cliffe & M'land	61	5.8%	27	10.7%	272	25.9%	105	41.5%
South East Holderness	202	10.7%	112	19.7%	648	34.3%	293	51.5%
South Hunsley	36	3.3%	18	10.2%	226	20.9%	80	45.5%
South West Holderness	94	5.9%	51	12.7%	414	25.9%	168	41.8%
St Mary's	92	5.2%	34	10.4%	461	25.9%	156	47.6%
Tranby	66	5.4%	27	9.9%	351	28.7%	126	46.2%
Willerby and Kirk Ella	88	5.3%	36	11.8%	433	25.9%	144	47.4%
Wolds Weighton	82	5.0%	34	11.3%	385	23.7%	126	41.7%
ERY	2331	6.3%	1107	12.9%	10280	27.6%	3863	45.1%

SACE survey 2016/17 - carer-reported quality of life

The section displays the questions asked during the survey which were then used to determine the carer-reported quality of life score. Each of the questions in table A3.30 has three possible answers, which are equated with having:

- no unmet needs in a specific life area or domain (the ideal state)
- some needs met
- no needs met.

Table A3.30 Questions asked to determine Carer-reported quality of life score. Source: SACE

Occupation – Q7	Which of the following statements best describes how you spend your time?
Control - Q8	Which of the following statements best describes how much control you have over your daily life?
Personal care - Q9	Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation?
Safety – Q10	Thinking about your personal safety, which of the statements best describes your present situation?
Social participation - Q11	Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?
Encouragement and support - Q12	Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?

Chart A3.31 Carer-reported quality of life from SACE survey (score out of 12). ERY compared to England and CIPFA neighbours, 2014/15. Source: PHE

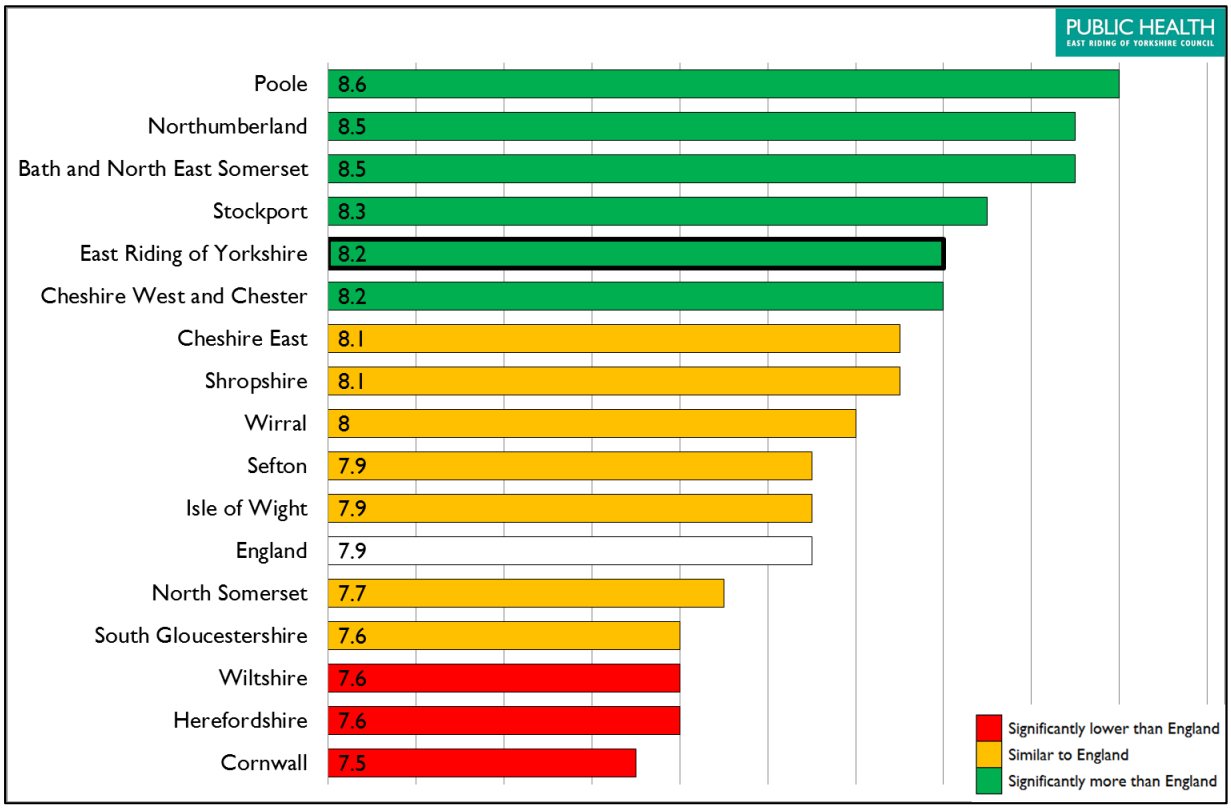


Chart A3.32 The percentage of adult carers who have as much social contact at they would like. ERY compared to England and CIPFA neighbours, 2016/17. Source: NHS Digital

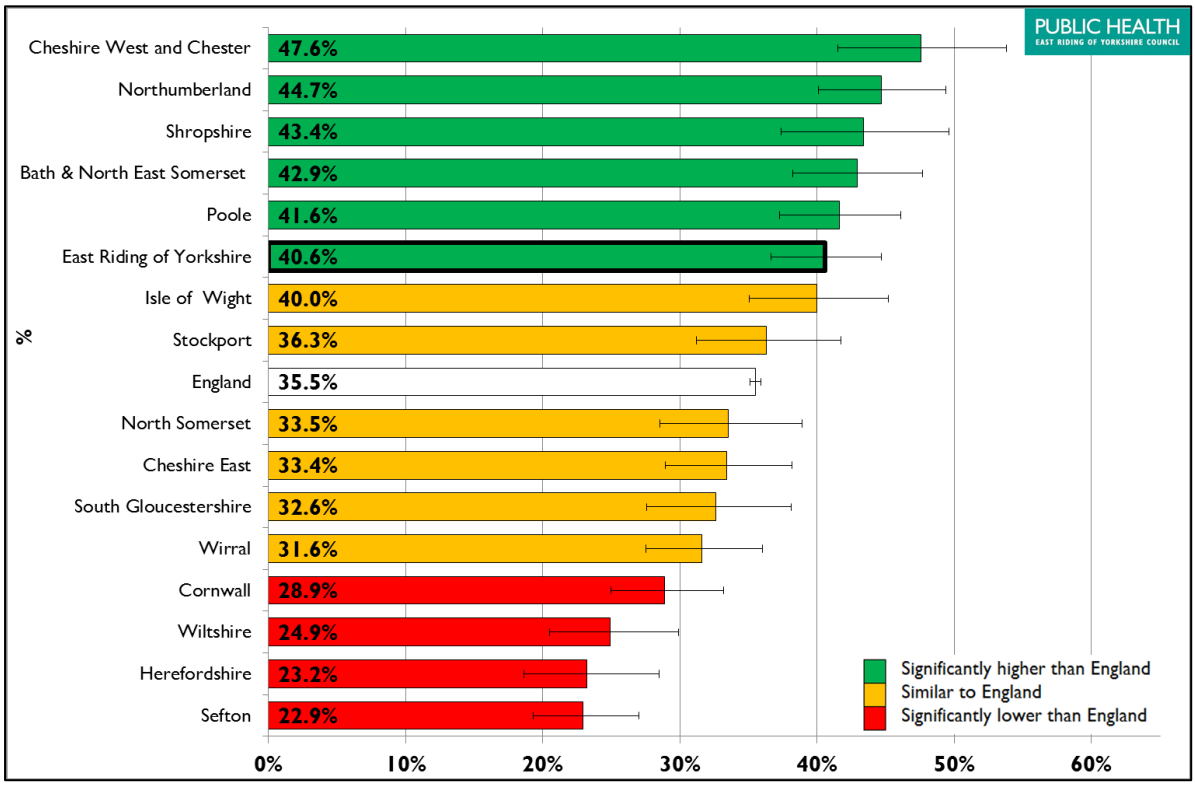
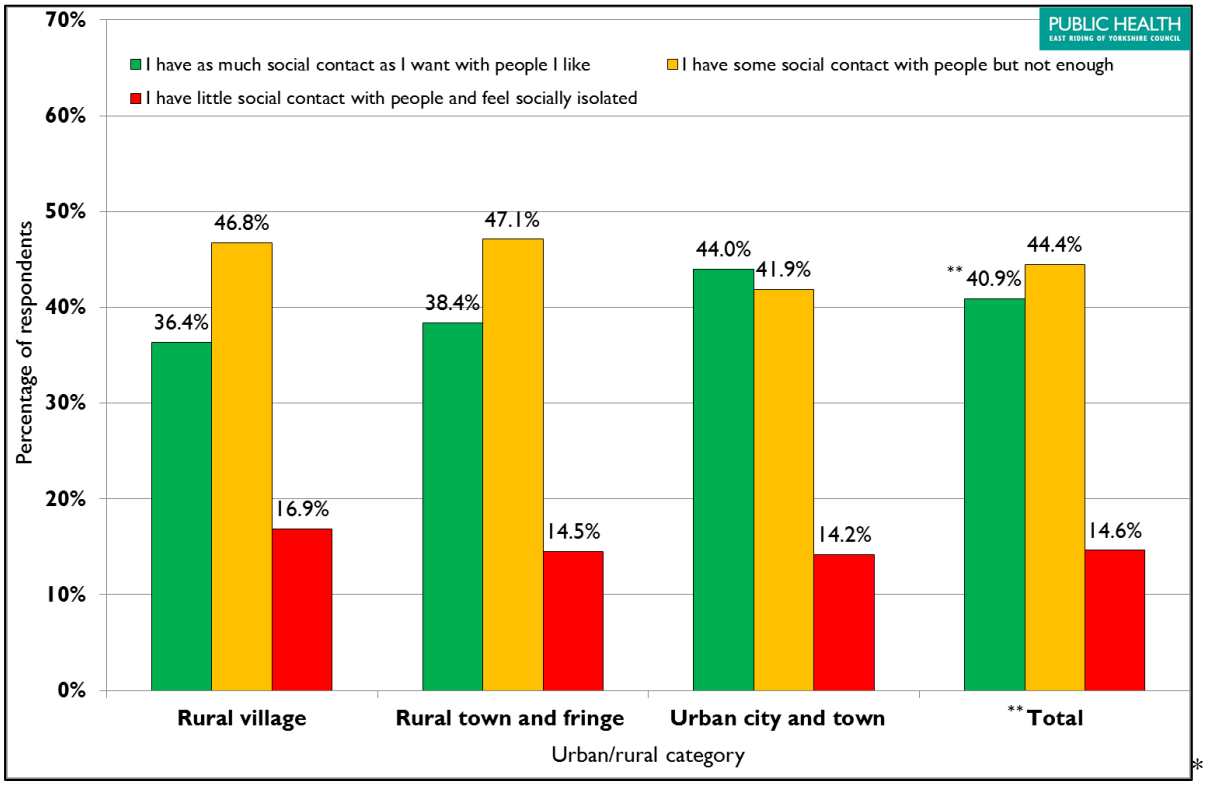


Chart A3.33 SACE 2016/17: Responses to Question 11 about social contact, by area of residence (urban/rural categories). ERY residents. Source: SACE survey*



** The "Rural hamlets and isolated dwellings" category was excluded due to extremely small numbers.*

*** The total in the chart is different from the overall reported total, as not all respondents had provided that could allocate their address an urban/rural address.*

Chart A3.34 SACE 2016/17: Responses to Question 11 about social contact, by area of residence (old CCG/JSNA localities based on groupings of ERY wards). ERY residents. Source: SACE survey

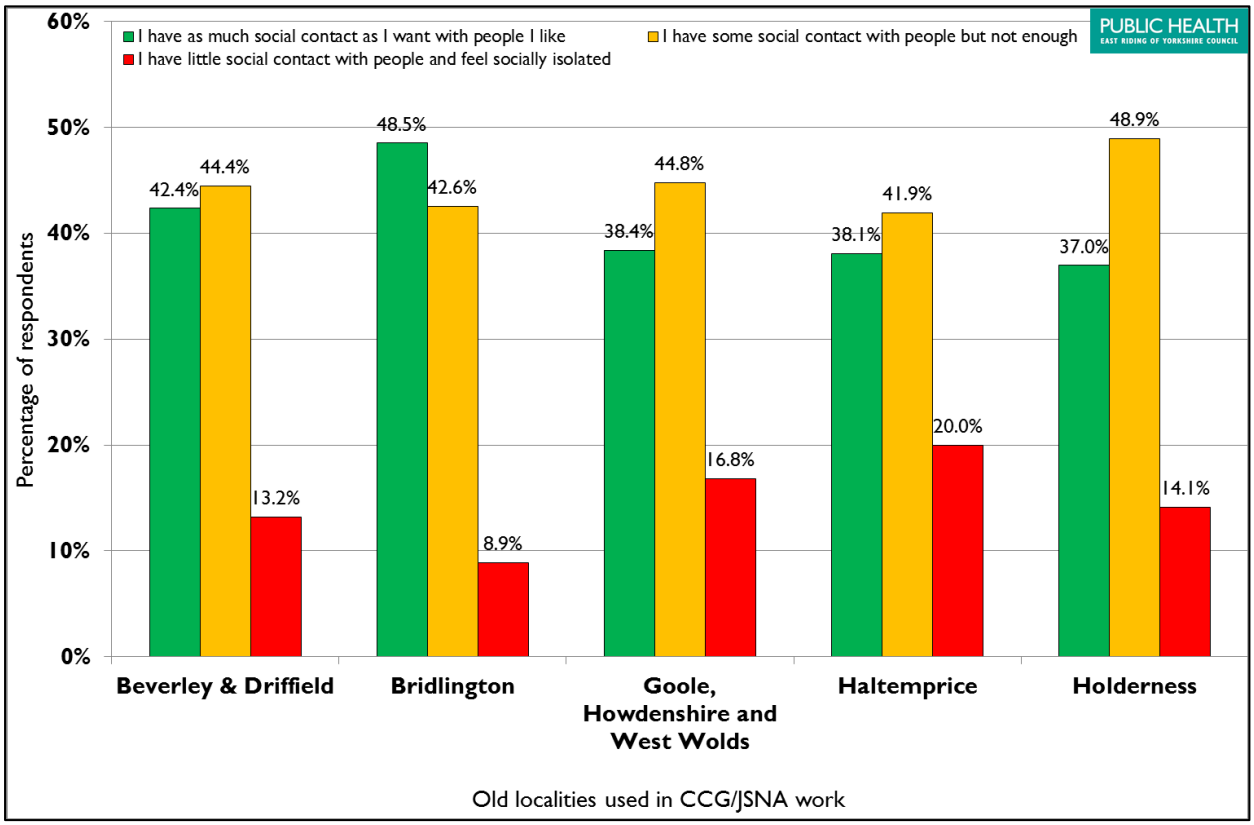
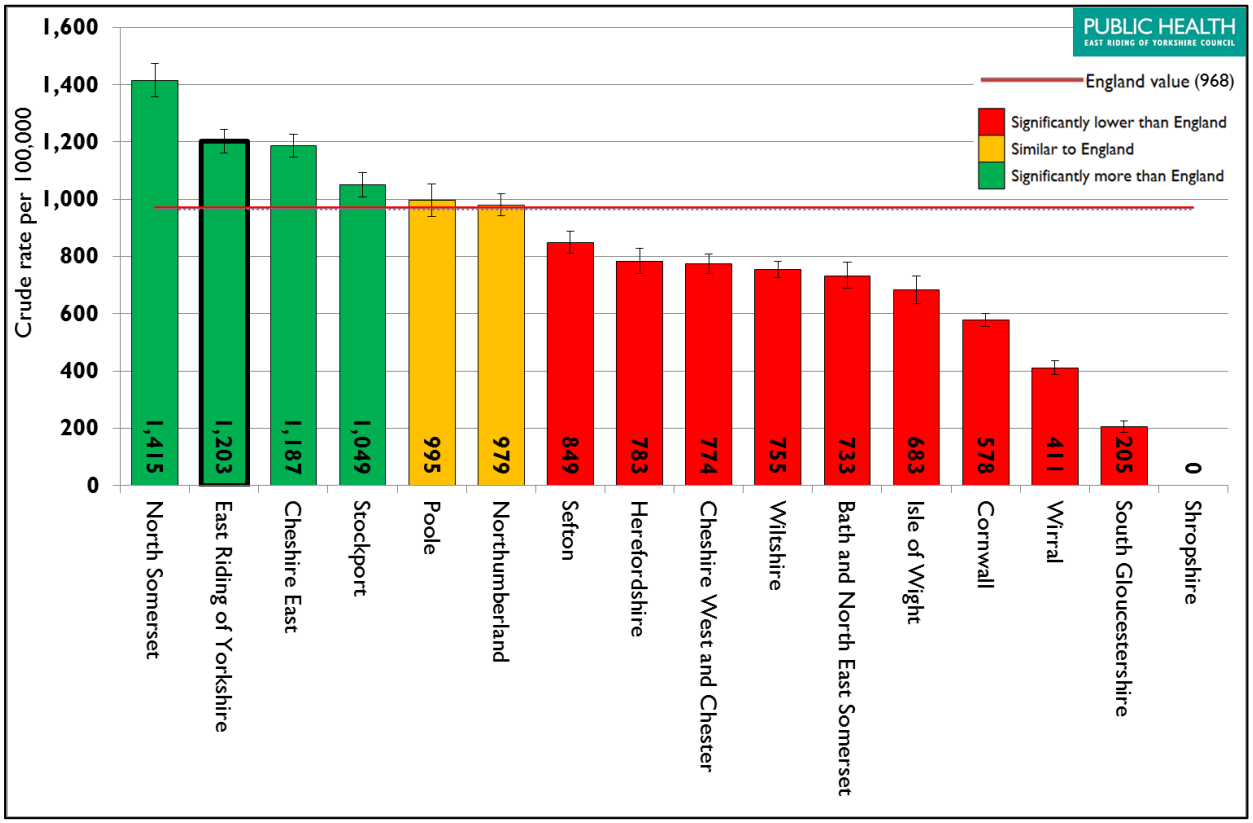


Chart A3.35 Adult carers receiving assessments crude rate per 100,000, ERY compared to England and CIPFA neighbours, 2013/14. Source: PHE*



**Note: this indicator is usually restricted to new carers coming to the attention of local authority services*

Chart A3.36 Assessments for carers of adult mental health clients, crude rate per 100,000. ERY compared to England and CIPFA neighbours, 2013/14. Source: PHE

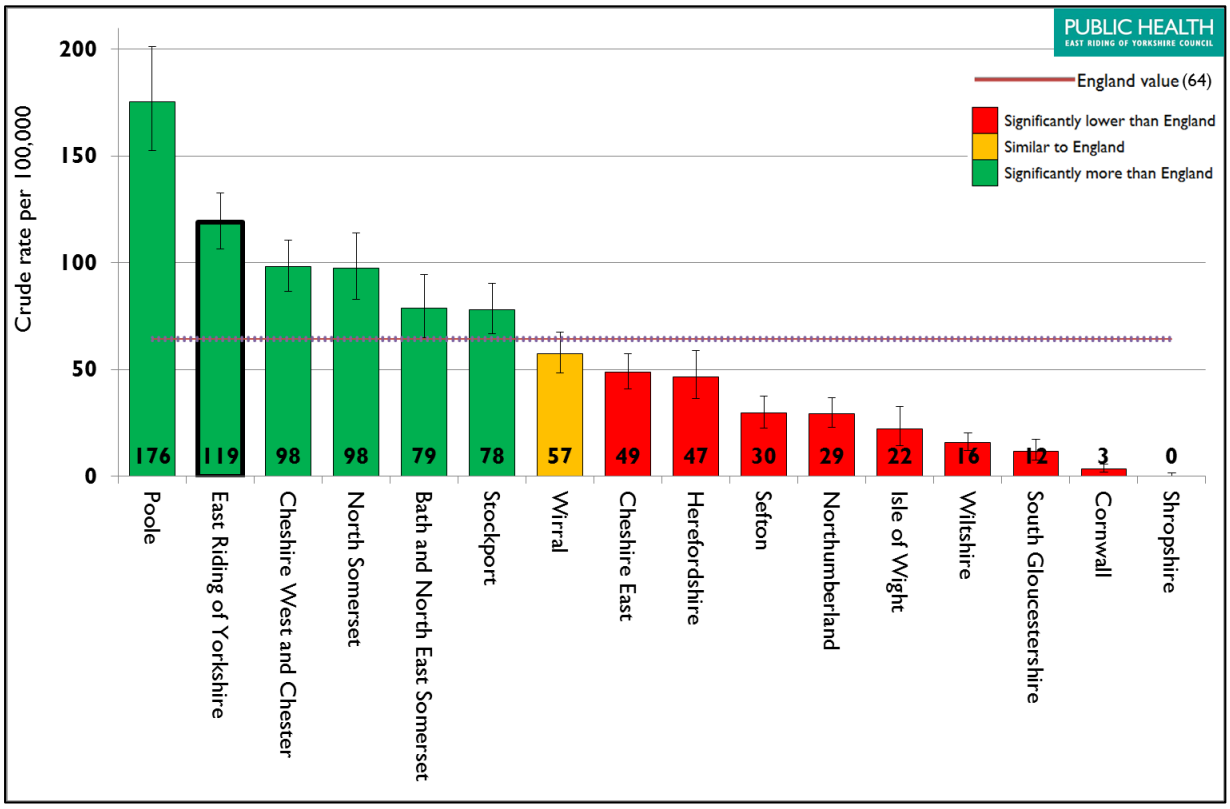


Chart A3.37 Overall satisfaction of carers with social services. ERY compared to England and CIPFA neighbours, 2016/17. Source: NHS Digital

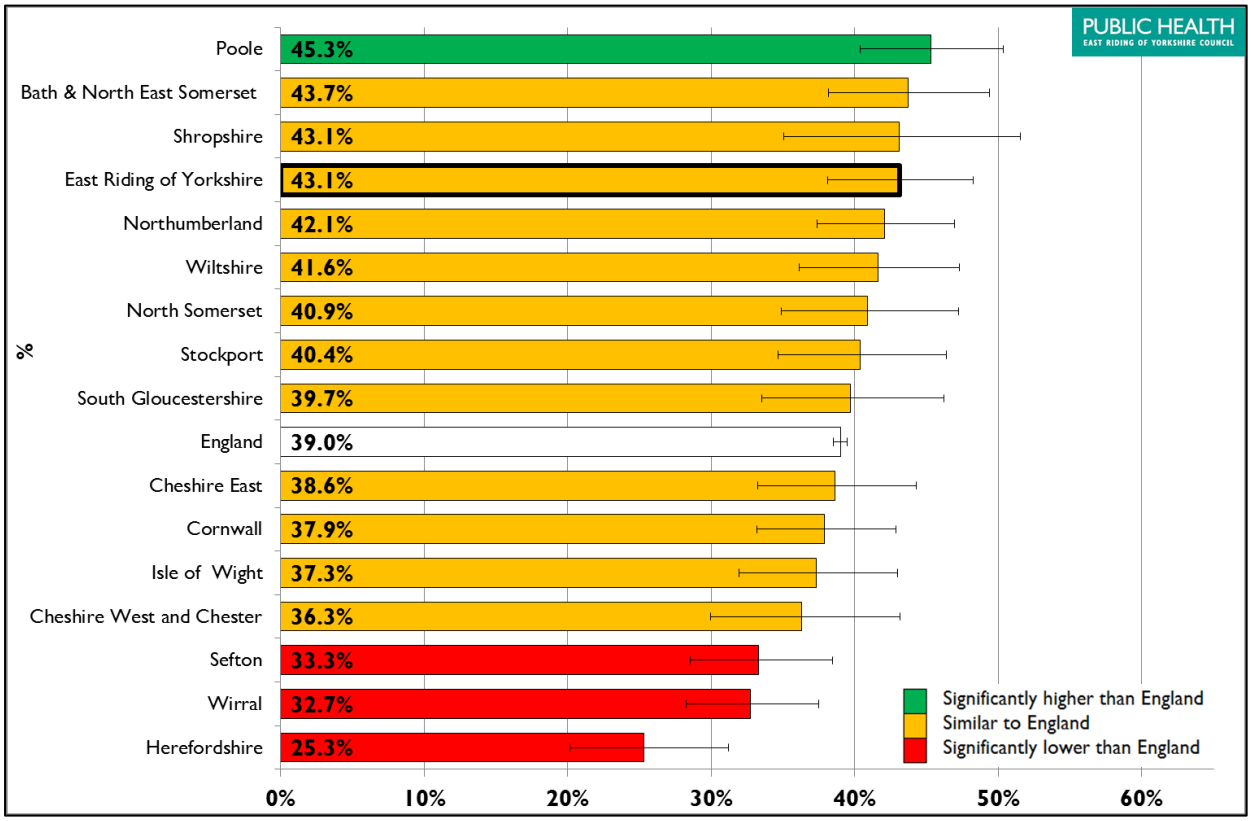


Chart A3.38 Percentage of carers who report that they have been included or consulted in discussion about the person they care for. ERY compared to England and CIPFA neighbours, 2016/17. Source: NHS Digital

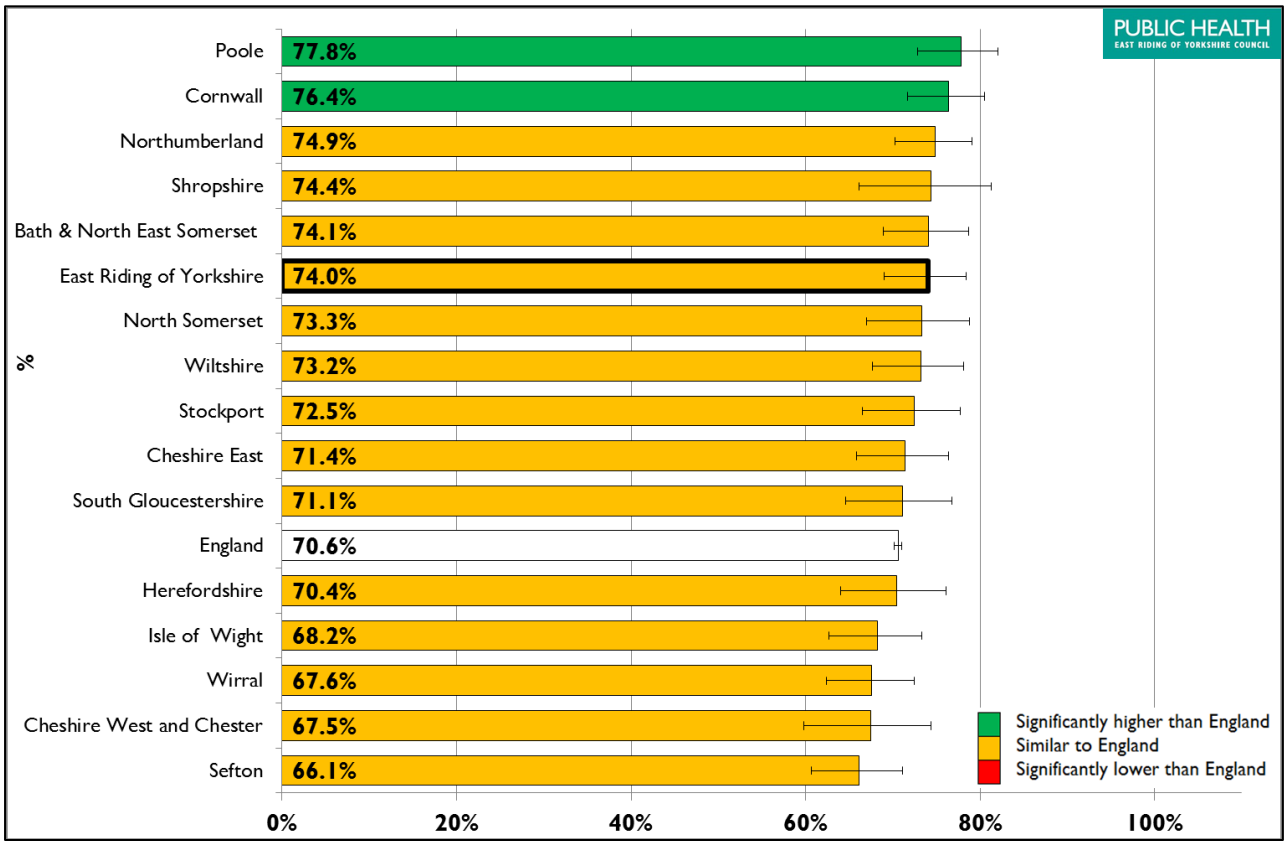
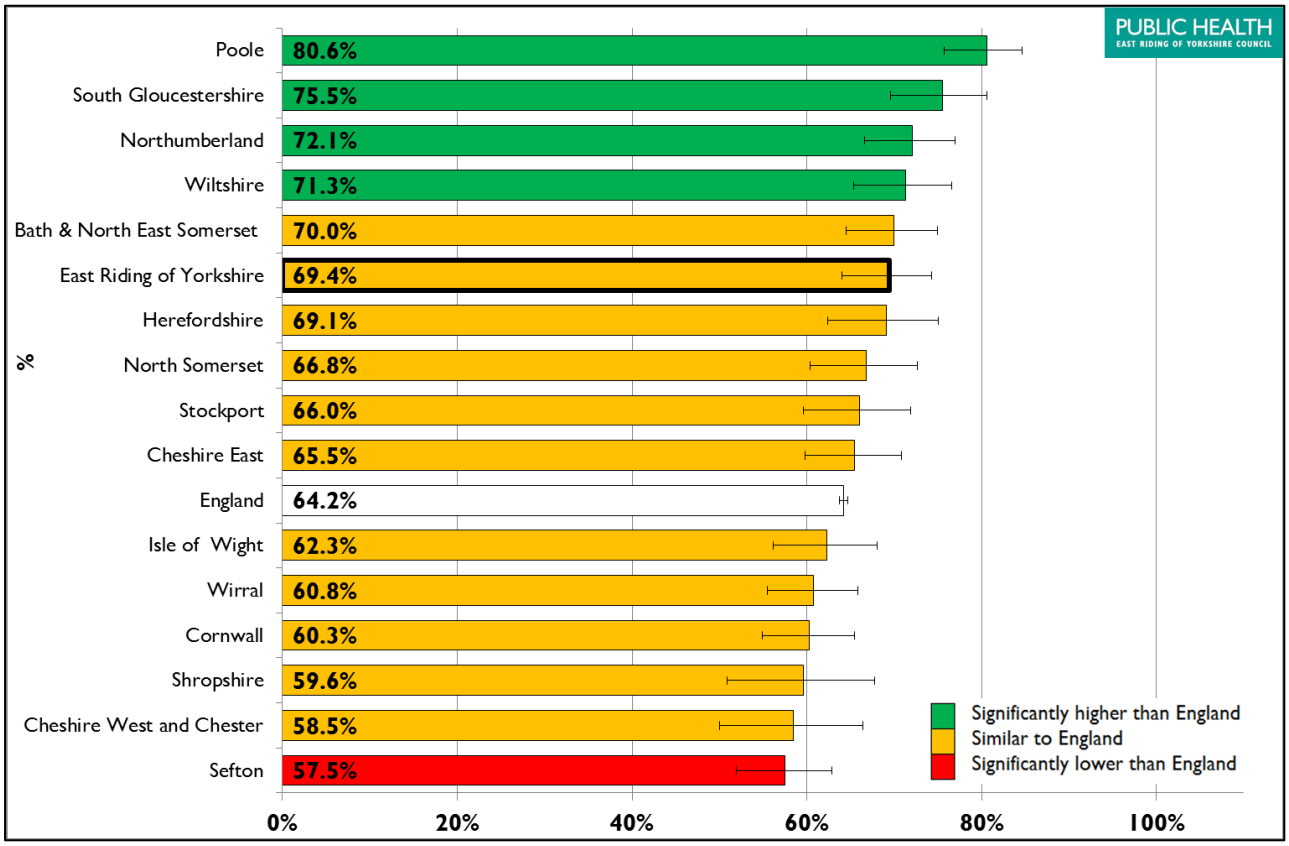


Chart A3.39 Percentage of carers who found it easy to find information and advice about support, services or benefits. ERY compared to England and CIPFA neighbours, 2016/17. Source: NHS Digital



Appendix 4. Survey of Adult Carers 2016-17 - summary of results by the Adults Performance Team (Resource Strategy)

Appendix 4.1

A4.1 ASCOF outcomes from East Riding of Yorkshire Council survey

The survey is used to populate five of the measures from the Adult Social Care Outcomes Framework (ASCOF). These are:

1D	Carer-reported quality of life
112	The proportion of carers who reported that they had as much social contact as they would like.
3B	Overall satisfaction of carers with social services.
3C	The proportion of carers who report they have been included or consulted in discussions about the person they care for.
3D2	The proportion of carers who find it easy to find information about support.

The ASCOF score does not directly correspond with the percentage answers to the questions.

ASCOF 1D: Carer-reported quality of life (ASCOF 1D),

The score is calculated using various questions from the survey about occupation, control, personal care, safety, social participation and encouragement and support.

Although the ERYC's ASCOF score has decreased from 8.2 to 8.1 (out of 12) it was better in each of these questions than the averages for England (7.7) or the Yorkshire and Humber region (8.0).

This is illustrated by the percentages recorded for the most positive choice for each of these questions..

% of respondent who chose the most positive option	7. I'm able to spend my time as I want, doing things I value or enjoy	8. I have as much control over my daily life as I want	9. I look after myself	10. I have no worries about my personal safety	11.I have as much social contact as I want with people I like	12 I feel I have encouragement and support
ERYC	23.0	29.6	62.2	89.9	40.6	42.2
England	19.5	25.0	54.9	84.1	35.5	36.3
Yorkshire & Humber	21.9	27.9	57.7	87.3	38.7	38.5

ASCOF 11 (2): Proportion of carers who reported that they had as much social contact as they would like.

Slight improvement in performance from 39.7% to 40.6%. This question (number 11) was not asked prior to 2014/15. The East Riding (40.6%) is slightly above the regional average (38.7%) and is above the national average (35.5%).

ASCOF 3B: Overall satisfaction of carers with social services (Q4)

At 43.2% is a slight decrease from 2014-15 at 45.9% (2012/13 result was 51.7%). The East Riding slightly above the regional average (41.3%) and the England average (39.0%).

Question 4 - Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?

Q4	no support or services from Social Services in the last 12 months	extremely satisfied	very satisfied	quite satisfied	neither satisfied nor dissatisfied	quite dissatisfied	very dissatisfied	extremely dissatisfied
ERYC	31.3	10.3	19.3	22.1	9.0	4.9	1.9	1.1
England	22.4	11.5	18.9	24.9	12.1	5.4	2.2	2.7
Yorkshire & Humber	25.5	11.4	19.3	24.2	11.0	4.5	1.8	2.2

East Riding of Yorkshire Council has a greater proportion of respondents who indicated they had no support or services in the previous twelve months than regional or England averages. Consequently the number of respondents who expressed a level of satisfaction/dissatisfaction is lower.

Combining the percentages of the three satisfied options and three dissatisfied options gives a broadly positive picture generally in line with regional and England averages.

	Satisfied (%)	**Dissatisfied (%)**
ERYC	51.7	7.9
Yorkshire & Humber	54.9	8.5
England	55.3	10.3

ASCOF 3C: Proportion of carers who report that they have been included or consulted in discussions about the person they care for (Q18).

The East Riding (74.0%) is in line with the regional average (73.6%) and is above the national average (70.6%). The East Riding score has decreased over the last three surveys:

2012/13	82.0%
2014/15	76.4%
2016/17	74.0%

Appendix 4.2 East Riding of Yorkshire Council survey details

Process notes

In East Riding of Yorkshire Council all responses were written and in English with no translated questionnaires issued.

East Riding of Yorkshire Council does not collect data on religion or sexual orientation as it is not a mandatory field for any of the national collections. The data quality report therefore shows a rate of 100% missing data for these fields.

The proportion of respondents who indicated someone helped them complete the questionnaire (5%) was lower than the England (9.4%) or Regional (7.7%) averages.

Response rates

The national response rate for 2016-17 was 41% (2014-15 was 44%) and 42% for Yorkshire and Humber. East Riding of Yorkshire Council had the second highest response rate in the region and one of only six nationally to achieve a response rate of over 60%.

1) North Yorkshire	66%
2) East Riding	64%
3) North Lincolnshire	52%

Response rates vary between questions and councils. The table shows a summary of the overall response rates for the 151 councils

England, 2016-17	**Number of councils**
Less than 30 %	11
30 to 35 %	31
35 to 40 %	26
40 to 45 %	23
45 to 50 %	26
50 to 55 %	20
55 to 60 %	8
More than 60 %	6
Total	151

East Riding of Yorkshire Council survey details

The population of eligible carers at the time of the survey was:-

Category	Number of Clients
Male 18 – 64	537
Male 65+	593
Female 18 – 64	1143
Female 65+	987
Total	3,260

The sample (determined in accordance with guidance) was 909. The number of returns required to meet the statistical validity requirement (+/-5%) was 344 and 582 completed surveys were returned.

The gender composition of the East Riding of Yorkshire Council responses were similar to the national average.

	England	ERYC
Male	32.2%	35%
Female	67.8%	65%

Survey Population

The East Riding of Yorkshire Council survey included all carers registered with the council including those who had not had a review or assessment in the preceding 12 months. Some council's reported having problems including carers from this later group in their sample. This difference in the make up of the surveyed populations is reflected in the responses to Question 5 which show ERYC has a consistently lower percentage of the cared for person using services in the last 12 months. Similarly for question 6 ERYC has a consistently lower percentage of the carers accessing support or services listed in the last 12 months. This would be expected due to the inclusion of carers who had not had a review or assessment.

Appendix 5. Professional and stakeholder views

Appendix 5.1 Carer Rights Day (Building Carer Friendly Communities) challenges, issues and solutions identified by stakeholders

Table A5.1 Carers Rights Day, count of issues by 'challenge' group. Source: Carers Rights Day 2016

Challenge (Grouped)	Number	%
Isolation – Social	29	17%
Health – Access	25	14%
Health - Carers Support	22	13%
Environment - Community Building	19	11%
Environment – Transport	19	11%
Environment - Aids, Adaptations and Services	18	10%
Environment - Technology / Internet	8	5%
Financial	8	5%
Environment – Housing	7	4%
Environment – Rural	5	3%
Environment - Carers Support	3	2%
Isolation - Carers Support	3	2%
Safeguarding	3	2%
Environment - Image of Health and Social Care	2	1%
Environment – Training	2	1%
Grand Total	173	100%

Table A5.2 Challenges, issues and solutions identified by stakeholders regarding carers. Source: Carers Rights Day 2016

Challenge	Issue	Solution
Environment - Aids, Adaptations and Services	Ability to organise more respite that is affordable.	
	Access to aids and adaptations in the home.	Knowing what is already available.
	Access to aids and adaptations in the home.	Connect to Support
	Access to respite involves long distances - we need night sitters rather than separation.	
	Accessing the right services.	Thorough discussions that determine the right solutions for both the Carer and the Personal Cared For.
	Availability of domiciliary care provision in area.	
	Communication for people with impairments.	
	Difficulty gaining physical access due to disabilities.	

	Knowing and having information on what is available.	
	People in isolated areas are hard to reach.	It would be good to have access to Professionals in local places, e.g. GP Surgery's, regular places, etc. rather than just leaflets.
	People in isolated areas are hard to reach.	Putting people / Professionals in Tesco's, Specsavers, etc. - a neutral space where people won't feel afraid to talk about their caring role with worries that they may have about Social Services.
	Raising awareness of what is available.	
	Resources and affordable warmth.	
	Responding to the needs and continuity of care to ensure individual needs are known and you build rapport.	
	Rurality and the distance Paid For Carers need to travel and the time they have available to provide support / care.	
	Safety around the home - identify any aid or adaptation requirements.	Access to Support Services in all areas.
	Safety around the home - identify any aid or adaptation requirements.	Knowledge of Lifeline and what aids and adaptations are available.
	Safety around the home - identify any aid or adaptation requirements.	Awareness of the financial assistance and assessments available to support aids and adaptations.
Environment - Carers Support	Encouragement as people do not like to ask for help or support. Need to encourage them and give them more confidence.	
	Knowing you are not alone as a Carer.	Give carers good press and sharing information so they know that others are out there doing the same job.
	Not classed as a Carer for a child until they are 18.	
Environment - Community Building	Access to Community Navigators	Train more Community Navigators.
	Access to monitoring and helplines	Headway have a monitoring service and helpline, access this and other services.
	Availability of Community Navigators.	

	Awareness of what is already available in the community	Give Carers and Cared For timely information at the beginning of their journey, e.g. Carers Assessments and other Services which are available in the Community.
	Community development.	Community development similar to Work Link activities and groups.
	Community development.	Building neighbourhood communities, such as Time Bank.
	Community support services in rural areas.	
	Difficulty finding information of what is available.	Promote Connect to Support.
	Difficulty finding information of what is available.	Identify and look at the community based assets.
	Difficulty finding information of what is available.	Look at making services as local as possible.
	Difficulty finding information of what is available.	Make use of services that are already there, e.g. Village Hall, Churches, etc.
	Difficulty finding information of what is available.	Signposting to local services.
	Difficulty finding information of what is available.	Have a *buddy system* that introduces people to the services, e.g. more befriending services.
	Lack of development of community activities.	Encourage community development.
	Lack of involvement of Carers, Service Users and Young Carers.	Activities are developed in consultation with Carers, Service Users and Young Carers.
	Lack of links between local services and main services.	Increase links and hubs between local services and main services.
	Lack of resources or knowledge of community based activities.	
	Links with neighbours within rural areas is a challenge.	
	Neighbourhoods are not *what they used to be*.	
Environment - Housing	Access to adaptations in the home. Safety in the home. Crowding in the home.	
	Appropriate housing.	
	Caring for people in unsuitable houses.	
	Housing for people not always suitable for people with needs.	
	Housing not suitable.	Specialist housing.

	Housing not suitable.	Access to Supported housing, e.g. extra care for those who do not want to move.
	People are isolated in their homes as they are not suitable for their needs.	
Environment - Image of Health and Social Care	Care Homes and Carers receive bad press, which can prevent people from trying to get help. How do we convince them that the bad workers are in the minority?	
	More health inspections.	
Environment - Rural	Ability to access different services from rural areas.	
	Coastal areas and communities.	Knowing what is already available.
	Geography of the area.	Knowing what is already available.
	Having facilitates that are accessible.	
	Limited infrastructure in rural communities.	Knowing what is already available.
Environment - Technology / Internet	Improvements to the Wi-Fi especially in the rural areas.	
	Internet access.	
Environment - Technology / Internet	It has been announced that there might be more/ better internet for our area, but for how many and who?	
	IT issues.	
	Lack of broadband and internet providers.	
	Lack of internet access and ability to use technology.	
	Lots of information is now IT based and older people do not have access to this.	
	Technology is OK, e.g. Sensors, but need a response. We need a range of technology.	ERYC Telecare responder service to help support.
Environment - Training	Training for Carers, e.g. Moving and Handling, Working with People with Dementia, Sight Loss, Identifying Risk, Accessibility, Being Safe, Community Awareness, etc.	Having an App for training Carers.
	Training within the Carers home - is it available if needed?	
Environment - Transport	Ability to travel to hospital.	Knowing what support is available. Medibus, Hart, etc.

	Amount of travelling when you live in rural areas.	
	Community transport and voluntary schemes to help with transport.	
	Cost of transport.	
	Difficulty getting person into transport	
	Further the services are away, the high the cost to access wheelchair taxis.	
	Lack of transport in all areas, particularly villages.	
	Limited transport in rural areas.	
	Long commutes to work.	
	Need to develop community transport.	
	Not been able to get to services - accessibility.	
	Rurality and transport issues/concerns.	
	Rurality issues of transport and less people who can help or be there for Carers. Restrictions of distances mean less visitors.	
	Time consuming using patient transport.	
	Transport in rural areas.	
	Transport issues.	
	Transporting the elderly on buses.	Using different services, e.g. Hart Bus, and different Church Groups with volunteer drivers.
	Travel from A to B	
	Weather can effect transport.	
Financial	Financial problems.	
	Knowing about Direct Payments and Personal Budgets.	Information about Direct Payments and Personal Budgets and how you can find local Carers.
	Knowledge of benefits and people to help you.	
	Lack of funding in the Voluntary Sector.	
	Lack of, or, affordable heating.	
	Low pay, unemployment, benefits and financial hardship.	

	People have lost the mobility component on their benefits so cannot about. People don't know how to fight for these benefits.	
	Support to access Direct Payments and Personal Budgets, as some Carers feel this is just another task.	
Health - Access	Ability to access GP appointments.	
	Access across ERY for people who have health needs	
	Access to information.	Access to health education.
	Access to information.	Telephone, website or App. Training for Carers.
	Access to services and / or information.	
	Accessing health visits.	
	Are the GPs treating the carers as people and taking the time to make sure that they are ok?	
	Getting to hospital / GP appointments.	
	Getting to hospital in emergencies - separation of couples, etc. this is a big issue and very worrying for the Carer.	
	GP awareness of mental health and deafness, which are an effect on Carers and the Person Cared For.	
	GP integral	
	GPs need to be flexible and consider the caring needs.	
	Health of Carers	Having an Annual Health Check for Carers.
	Health Services being flexible for carers.	
	Lack of training or knowledge.	
	No one to look after the Person Cared For when attending hospital.	Castle Hill Hospital have a service where they can sit with the Person Cared For whilst the Carer has cancer treatment.
	Not being able to book appointments in advance.	
	Not enough advertisements of local health groups, e.g. walking for health.	

	People need to ring and find out about what services are available if treatment is needed for the carer.	
	Professionals being able to visit homes.	
	Services not always accessible due to mobility.	
	Social prescribing NHS.	
	Supporting carers of children under the age of 18.	
	There are limited services for the person accompanying the patient to appointments.	
	Visits to the home.	
Health - Carers Support	Accessing the right support.	
	Addiction smoking drinking coping with the anxiety and stress put them selves first and looking after their own health and wellbeing.	
	Carer more worried about the Person Cared For.	
	Carer not looking after themselves, what can help them?	
	Carers not acknowledged.	
	Carers not looking after their own health and wellbeing.	
	Carers putting Person Cared For before themselves.	
	Carers unaware of what is available.	
	Contacting specialist groups.	
	Depression, stress, alcoholism and anxiety.	
	Encouragement of personal care.	
	Encouragement to get a carer into health groups but also giving them the confidence to do things for themselves.	
	Having an impact on mental health and depression.	

	Looking at other support groups and chat about their own experiences, having discussions with other carers and not making them feel they are the only ones in this situation, but then again having the respite provided to enable them to attend the support groups.	
	Need support.	Having a Carers Network.
	Need support.	Combine groups to enable to share all experiences.
	Need support.	Bring positive stories so a facilitator within a group to organise and make sure there are not just negative feedback.
	Need support.	Telephone support and befriending services to support not only within the groups but at home.
	Psychological issues.	
	Restricting you physical and emotional wellbeing.	
	Sleep deprivation.	
	Stress of being a carer.	
Isolation - Carers Support	Not having time or wanting to go to doctors or operations because off their caring role.	
	Someone to sit with the Cared For person when the Carer needs to go out, etc.	
	Someone to sit with the Cared For person when the Carer visits the GP.	
Isolation - Social	Access to shops and services.	
	Access to shops.	Internet shopping through Age UK.
	Access to support for those with dementia.	More dementia groups / memory cafe for carers.
	Access to support.	Services such as U3A, Women's Institute could be used to appeal to a bigger audience.
	Access to support.	Buddy systems, lifestyle coaching to change behaviours, encourage neighbours to get chatting, small groups in rural areas, time bank.
	Adverse weather, which brings isolation.	
	Carers need a voice.	

	Caring because they are Husband or Wife.	
	Changing your life around to be a Carer, e.g. working from home, reducing hours, etc.	
	Family dynamics.	
	Family members who are carers.	
	Feeling isolated.	Befriending service through the Royal British Legion.
	Feeling isolated.	Knowledge of what is already available.
	Financial impact.	
	Health of Carer and Person Cared For can deteriorate, no / low stimulation makes it difficult to motivate people to go out.	
	Impact on relationships.	
	Internet can be good, but also isolating, e.g. shopping online and not going out to meet people at the shops.	
	Isolation in rural areas.	
	Lack of befriending services in the area.	Befriending service through the Royal British Legion.
	Lack of socialisation.	
	Lack of support for young carers to stop them feeling socially isolated.	
	Loosing confidence and self esteem.	
	Loosing confidence and self esteem.	Carer relief service.
	Loosing confidence and self esteem.	Telephone support.
	Parents with children with difficulties.	
	Social isolation.	
	Support for parents of carers.	
	The more you stay in the Carer Role, the less you can be involved with others and you do not know what support is available.	
	Virtual chat groups (varying communication methods).	
Safeguarding	Being an easy victim to abuse.	
	Being vulnerable.	
	Risk off abuse, falling and having no help.	

Appendix 5.2 List of carer pledges from Carer Rights Day (Building Carer Friendly Communities)

Table A5.3 carer pledges from stakeholders at the Carers Rights Day.

Pledge	Organisation
To give the ongoing support to the carers of veterans of the Armed Forces. To continue to promote and reach out to the hard to reach communities to support with all welfare needs.	Royal British Legion
To find out about all the services that can help make their lives better and more manageable.	Royal British Legion
We will remember carers when reviewing the Better Care/VCS Mode I "Social Prescribing" ensuring support for participant and carer.	HURCC
To promote carers support more in my day to day services. Widen my knowledge of voluntary services in the area and use these more frequently.	
Try and make life a little easier, where I can.	ERYC Trading Standards
To promote carers and continue to drive carers through Adult Services ensuring the good work and commitment is maintained.	ERYC
Encourage all unpaid carers to register for help and support.	Carer
To provide continued support and reassurance.	Beverley CMT
Increase awareness of the needs of carers and the help and support that is available.	
To listen and sign post any carers who need support to the right services.	Humberside Fire and Rescue
To always remember to take carers into consideration when supporting people at the Red Cross.	British Red Cross
To offer support and information to people with brain injury, their families and carers.	Headway Hull and East Riding
Support, refer and improve quality of care to both carers and the cared for.	HERIB
To use more of my time completing carers assessments and care plans.	
Provide and improve the services we support carers with. Also to supply our carers with the information we received today.	ERYC
To continue to identify carers and sign post to relevant services. To make the experience of our service more easy for carers and for the people they care for.	Humberside Breast Screening
To develop a 'Carers Charter' in partnership with carers of people who use our services.	HFT
To continue to work to improve the lives of carers though information and advice.	Alzheimer's Support Society
Provide information for carers to maintain positive health through screening.	Bowel Cancer Screening
To ensure Lifeline Technicians are providing information to carers around support and service available to them.	EYRC
Improve health and wellbeing to all carers and work hard to target the many unregistered carers in the East Riding.	NHS Healthtrainers
To work via HART to provide transport links to reduce rural, medical and age related isolation.	HART
To help to stop social isolation in the Holderness rural area. With the hope that this can lead to a better health state for carers and others in the community.	HART Holderness Area Rural Transport
To look more in-depth into what is available in my area so I can signpost better.	Goole CMT

Identify carers in the community. Offer/complete carers assessments. Offer services and provide them. Give advice/information.	Bridlington CMT
Raise awareness of carers issues in colleges/HYMS etc.	CAG
Pass on what I have learnt today and take it into the community to the vulnerable.	Humberside Fire and Rescue
Stop and listen. I endeavour to help you where I can.	ERYC
Please ask the question, if ever you need help or support don't be afraid to approach people or be that private person, we are here to support all.	CSS
Always be there for carers and give support and advice. Use other services to help them.	Carers Support
To continue listening to carers and supporting them in achieving their goals.	CSS
To gather further information to contribute to knowledge and use of services for individuals and their carers.	
To continue to identify carers in need of some support and ensure the correct and appropriate support is provided where possible.	Bridlington CMT
Plan and run more community-based social activities to provide carers with an outlet to take part.	Timebank Hull and East Riding
To look at how parents and carers of young people with profound needs are better recognised and supported, To dispel the myth that parental responsibility means you have a duty to care to the point it has a detrimental effect on your emotional and physical wellbeing.	ERYC
Pass on the information to my team, that I have learnt today and get them to pass on the word.	DRT
Progress the strengths based approaches to support carers in their communities.	ERYC
Collate the information. Share and build the carer friendly community.	ERYC Carers support
Carry on caring instead of being cared for (aged 83)	Hornsea Hospital League of Friends
To continue to improve the Hornsea United Reformed Church Living Well Project in assisting those who feel isolated to become more active in the community.	HURC Living Well
Discuss your concerns and signpost to support.	
To work with providers to make them aware of the services available to carers and encourage more to identify carers with unmet needs.	ER CCG
To carry on caring.	
To be a link worker, the Carers Support Service and joint work with other services, improve access.	IAPT
Listen, react and respond, support.	Beverley CMT
To offer and complete carers assessments. To promote carers right to an assessment and, if eligible, a service/direct payment to support them in their role.	Haltemprice CMT
Promote services available in which they are not aware of. "LISTEN".	British Red Cross
To always be available to listen and support when possible.	MIND
Make libraries more 'carer' friendly. Ensure all information is more accessible and somewhere easy to find in branches. Make sure staff are more 'carer' friendly.	ERYC Libraries
To look at getting something set up for young carers that support their health and wellbeing (funding dependant).	ERVAS
Meet with CSS to discuss more partnership working.	ERYC Leisure

Appendix 5.3 Healthwatch 2017 carer survey results

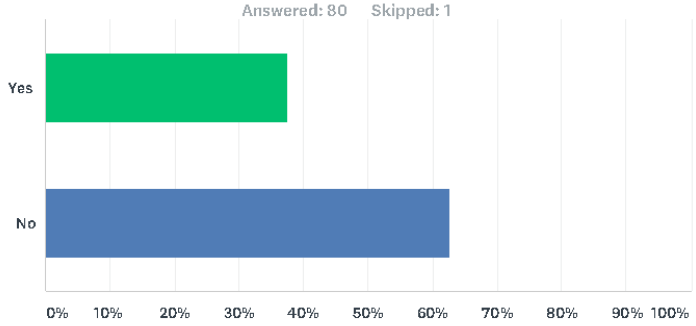
This section provides the results of the 2017 Healthwatch carers survey:

Q1 What is the first part of your postcode? e.g. HU15

Answered: 52 Skipped: 29

Q2 Are you an unpaid carer?

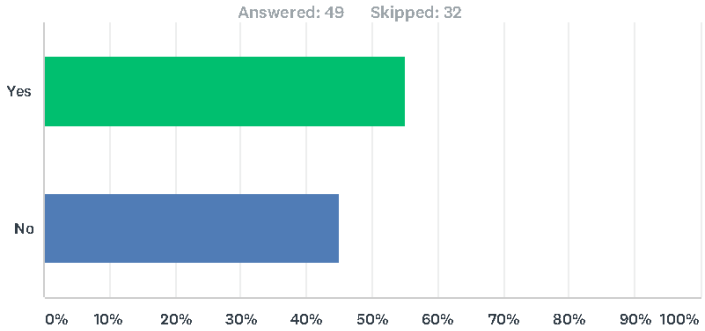
Answered: 80 Skipped: 1



Answer Choices	Responses	
Yes	37.50%	30
No	62.50%	50
Total		80

Q3 Do you know any carers?

Answered: 49 Skipped: 32



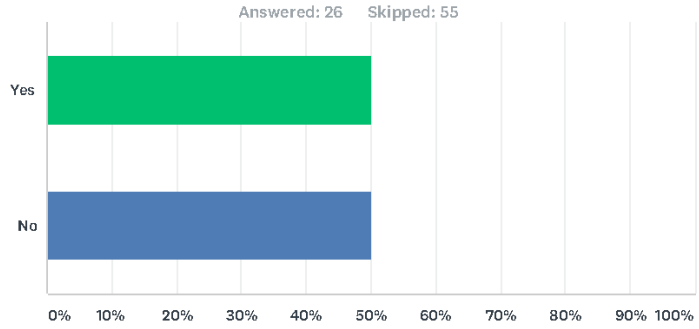
Answer Choices	Responses	
Yes	55.10%	27
No	44.90%	22
Total		49

Q4 What relationship do you have with the person(s) you care for?

Answered: 22 Skipped: 59

Q5 Do you get support?

Answered: 26 Skipped: 55



Answer Choices	Responses	
Yes	50.00%	13
No	50.00%	13
Total		26

Q6 If you answered yes, who do you get support from?

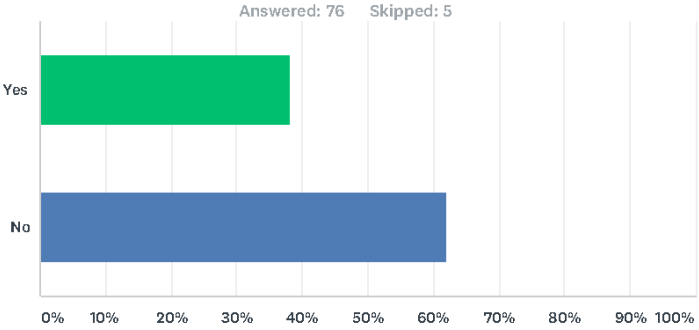
Answered: 13 Skipped: 68

Q7 If you answered no, why don't you get support?

Answered: 13 Skipped: 68

Q8 Are there any barriers preventing you from accessing services?

Answered: 76 Skipped: 5



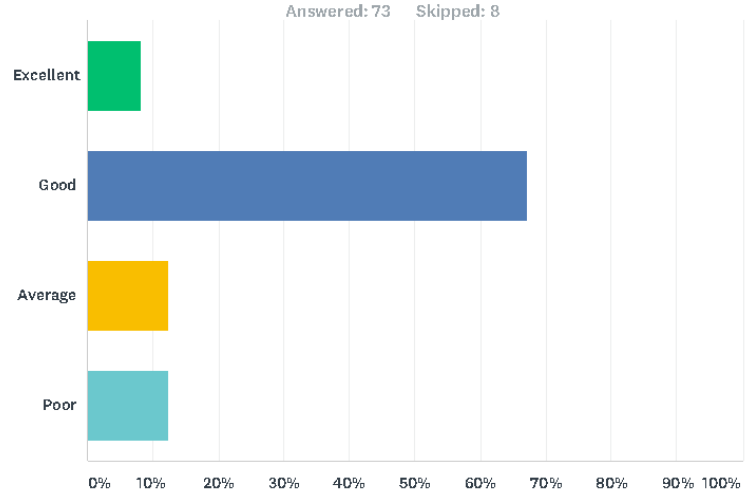
Answer Choices	Responses	
Yes	38.16%	29
No	61.84%	47
Total		76

Q9 If you answered yes, what are the barriers?

Answered: 28 Skipped: 53

Q10 How would you rate your local Health & Social Care services?

Answered: 73 Skipped: 8



Answer Choices	Responses	
Excellent	8.22%	6
Good	67.12%	49
Average	12.33%	9
Poor	12.33%	9
Total		73

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