The Scottish National Lifecurve[™] Survey: Costs of functional decline, opportunities to achieve early intervention to support wellbeing in later life and meaningfulness of the Lifecurve[™].

Abstract

Objectives

The aim of the Scottish AHP LifeCurveTM Survey was to gather a snapshot of where people are on their LifeCurveTM when receiving an Allied Health Professions (AHPs) services and to understand the cost consequence of intervening 'late' in the ageing trajectory. The objectives were to promote discussion around preventing functional decline, support innovation in service delivery and facilitate broader engagement with individuals, communities and wider environments for improving health and wellbeing in later life. In addition, subsequent learning could help address the increasing resource gap between demand and capacity across health and social care.

Study Design

The survey was paper based in the form of a printed booklet which contained the fifteen activities of daily living (ADL) and instrumental activities of daily living (IADL) which comprise the LifeCurveTM with additional lifestyle questions and information about the member of staff and service the participant was seen in, including their Community Health Index (CHI) number. The survey questions and booklet layout were tested over a five-month period with AHPs and people receiving AHP services. Liaison with national Health Literacy colleagues and lead speech and language therapists ensured that the survey material was accessible to a wide range of people. In addition, the survey could be made available in alternative formats on request.

Methods

Agreement to undertake the National Survey was obtained in November 2016 by all AHP Directors and Associate Directors who appointed Communication Support Leads in their area who would support implementation at all stages at a local level. All materials relating to the survey were published on a dedicated area of a Community of Practice to support awareness and training during the pre-implementation phase. AHPs working in adult services were asked to complete a survey with a minimum of two people they would 'typically' see in their service during a two-week period in May 2017 with the exclusion of people who were too unwell to participate, children and young people under 16 years and adults with incapacity and without a guardianship arrangement in place. Approval was gained from the Public Benefit Privacy Panel to link the survey data to participants' health service usage using their CHI number. Completed forms were returned to the University of Strathelyde for entry into an encrypted electronic database using a double data entry process and were allocated a unique identifier. The unique identifier and CHI numbers were sent to Information Services Division (ISD) and then the CHI numbers were deleted from the encrypted database. ISD sent the linked health data to the Scottish Government Analytical Services Division which thus produced a full encrypted and anonymised database.

Results

The data explains what stages on the LifecurveTM AHPs are intervening and the matched data provides associated health care costs at each stage. Due to poor or missing data in the AHP/Service section, only 60% (n= 8,261) of the total completed surveys were able to be matched with health service usage records. This data shows that whilst AHPs are seeing people at each of the fifteen ADL/IADL stages on the LifecurveTM interventions fell into three groups where 25% of people where seen at the 'pre-curve' stage, 13% of people at 'mid-Curve' (stage number five) and 39% of people at 'late-curve' (stages ten to thirteen). The health care cost usage of these participants increased the further along the LifecurveTM a person moves, with an average annual cost of £2,700 at 'pre-curve' rising to £12,330 at 'late-curv' in 2016-7. The results indicate that different services and professions are represented at each of these three points. So, for example, as might be expected outpatient (especially musculoskeletal) services were seen more often at the 'pre-curve' stage; Diagnostic Radiographers and Orthoptists saw people at 'early-curve' stages, Dieticians and Podiatrists saw people at the 'ind-curve' stage, whilst Physiotherapists, Speech and Language Therapists and Occupational Therapists saw people at the 'late-curve' stages. Data analysis showed this pattern is different for people receiving mental health services and so their data was removed and will be analysed and reported separately.

Conclusions

It is clear from the results that health care costs increased as participants moved down Lifecurve[™] stages i.e. as their levels of functional decline increase. It is also clear that AHPs are intervening late in a person's functional decline with associated limitations on changing their ageing trajectory. The cost consequence of this is significant – moving someone from 'late to mid-curve' could save £3200 per person per annum. However, those AHPs typically associated with re-abling approaches and rehabilitation which have greatest potential to change ageing trajectories were not represented at the 'mid-curve' stage (eg Physiotherapists, Occupational Therapists). Therefore, we must find places to have conversations with people to inform them that functional decline is malleable and not inevitable purely by virtue of chronological age; provide education and support to prevent or reverse functional decline and collaborate around strategic planning and commissioning to offer different options which support an optimum Lifecurve[™].

Keywords: healthy ageing, functional decline, activities of daily living, prevention, wellbeing

Introduction

The "Active and Independent Living Programme" (AILP) is an Allied Health Professions (AHPs) led national improvement programme whose aim has been to maximise the contribution that AHPs make to the health and wellbeing of the population of Scotland (1) and has formed part of the Scottish Governments' policy to improve public health (2). This paper sets out a potential framework for a system wide redesign utilising the initial results of the Scottish AHP LifeCurve[™] Survey (3) carried out in 2017.

The global population is getting older, with those aged 80 and over expected to increase threefold across the world by 2050 (4). Healthy ageing is defined "as the process of developing and maintaining functional ability that enables wellbeing in older age" and is a global health priority (5). The compression of functional decline has been widely reported (6,8,9) including in the Newcastle 85+ Study where the order of functional loss was described within a cohort of the study participants (7). The LifeCurveTM was subsequently developed as a framework which articulates this hierarchic loss to support prevention of functional decline and change in ageing trajectories (6). It lists in order the fifteen Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) described in the Newcastle 85+ study (7) which Gore and colleagues state "has been demonstrated by a number of cross-sectional and longitudinal studies, and across different age-groups, genders and populations 6". The advantage of identifying this order is considerable as "it supports the design of services targeted at the stages of progress of disability rather than at specific ages" (6). People are referred to AHP services as a result of some degree of functional loss and this study seeks to examine these same stages of loss in those people. A persons' position on their LifeCurveTM is obtained by recording which of the fifteen ADL/IADLs they are able to do without help from a person or use of equipment with their position being the lowest functional ADL/IADL they are able to do without any help. To enable active ageing, we need to recognise that action should be taken at an earlier stage than previously thought (9) and help develop public understanding that ageing is "more malleable than we used to think" (10).

Aim

The aim of the Scottish AHP LifeCurveTM Survey was to gather a snapshot of where people are on their LifeCurveTM when receiving AHP services and to understand the cost consequence of intervening 'late'. The survey results were aimed to support innovation in service delivery and broader engagement for improving health and wellbeing in later life. In addition, subsequent learning could help address the increasing resource gap between demand and capacity across health and social care.

The key questions to be addressed in this paper are:

- is the hierarchy of functional decline as described by the LifeCurve[™] and its' impact on ageing trajectories meaningful and understandable by AHPs and people using their services?
- 2) at what LifeCurveTM stage/s are AHPs intervening?

- 3) how much does the sequential loss of function as measured by the LifeCurve[™] increase health service delivery costs and what are the long-term savings in health costs which could be expected from preventing decline and regaining function at each LifeCurve[™] stage?
- 4) is there an economic argument for redesign using the LifeCurve[™] as a framework for change?

Methodology.

Recruitment

In June 2017 there were 13,676 AHPs (WTE 11,500) working in Scottish NHS settings, with approximately 600 employed by local authorities mainly in social work services. AHPs consist of twelve distinct professions with considerable variation of professional role, setting and intervention type (11). The survey was undertaken during a two-week period in May 2017. Survey research has been defined as a strategy rather than a research method (12) and the survey population was identified using non-random sampling (13) in that it included all adults receiving AHP services in both health and social care services in Scotland with the following exclusions: people who lacked capacity under the Adults with Incapacity (Scotland) Act 2000 and did not have a guardianship arrangement in place, people who were receiving palliative care, at the end stages of life and/or were too unwell to participate and children and young people under 16 years. All AHPs working in adult health and social care services in Scotland were asked to select two people receiving their service during the Survey period who they deemed to have a 'typical' or routine presentation.

Survey Design

The survey was presented in a printed booklet with easy read versions of the background/purpose and consent forms and comprised two sections: one for service users to complete (on their own or with help from family/friends or staff) and one for AHP staff to complete. Service users were asked to identify where they were on their LifeCurveTM at the time of the survey by self-reporting their ability to carry out the fifteen ADL/IADLs which were set out in a non-hierarchal random order (i.e. not in the identified order of loss). Self-reporting (with or without carer support) for ADL/IADL performance can be challenged for subjectivity, for example Mlinac and Feng suggest carers can overestimate the time taken for support (14). However, it continues as one preferred methodology not least as it has been shown to be of greatest benefit to the individual (15). The questions were set out as 'can you' rather than 'do you' in order to have "greater capacity to assess true levels of disability" (7, 16). It was recognised that for some participants their inability to carry out some of the ADL/IADLs would be temporary due to an acute or short-lived event. Good survey design only asks what it needs to know and not what it would like to know (17) however, given the unique opportunity to engage with AHPs across Scotland, additional data about the persons' wider circumstances and AHP services attended were collected to better inform any future service redesign. This expanded data set together with the pre-survey pilot activity is documented in the full protocol (18). Of relevance to this paper were data on the person's age, the profession of the service provider and the person's Community Health Index (CHI) number. The CHI number allows record linkage health records and associated health care costs. The survey design followed the twelve principles outlined by Jones et al (19), while consent and background information was informed by the General Medical Council Good Practice in Research and Consent in Research Guidance (20). Informed consent to share data anonymously was gained from

participants and permission to link data was given by the Public Benefit Privacy Panel (PBPP) for Health and Social Care situated within NHS Scotland's Information Services Division (ISD) (21).

Data collection

Given the number of AHPs across Scotland the national survey was identified as the best data collection method (19), and as many AHPs have no routine access to IT technology the survey was paper-based. Full details of the study protocol and implementation are available in the supplementary electronic resources to this paper (18).

Completed forms were returned to the University of Strathclyde for entry into an encrypted electronic database. Data were entered using the recommended double data entry process and data matching to eliminate data entry errors (22) with each completed survey allocated a unique survey number. Once all data had been entered the unique survey number and the associated CHI number for that individual were extracted and sent to ISD who used this to link to participants' health records data which included hospital in-patient admissions and outpatient appointments for physical health, mental health and women's health, accident and emergency episodes and community prescribing. Strathclyde University then deleted the CHI number from their records, retaining only the unique survey participants was then extracted from ISD health records and linked to the original anonymised survey data using the unique survey number for the appropriate survey record. This combined data set was held within Scottish Government Analytical Services Division. In this way an anonymised, encrypted and secure database of the survey information linked with the health records data was created.

Survey Limitations

The survey, although unique in that nothing comparable has previously been undertaken by AHPs, who comprise the third largest professional group working in health services in Scotland, has several limitations. Some sample bias is unavoidable e.g. people chose whether to participate or not, therefore, it was not possible to completely address bias to ensure the survey sample was representative of the AHP service user group (13, 23). In addition, ISD, to date, have not collected and reported on AHP activity data although work is currently ongoing to address this (11) so comparison data for those not participating does not exist. Further, given the wide range of service user characteristics across all twelve professions, AHPs were asked to use their clinical judgment to identify people to take part. The common qualifying criteria being to choose participants who were 'typical' or in other words had a routine presentation within their service. Direction was given to encourage people to complete the survey independently, to get help from family if required or where this was not possible (for example in some learning disability services, or where people did not have family members) for staff to offer support to complete. Either method could potentially introduce further bias (14). A number of measures were put in place to attempt to address limitations as far as possible within available time and budget parameters. This included a five-month pre-implementation process where a range of mechanisms were employed to communicate with the AHP workforce: local communication leads identified by AHP Directors, regular WebEx sessions, face to face meetings and use of an online community of practice (3). During this period the survey documentation was tested and refined with staff and service users and an FAQ developed to minimise differences in implementation across the twelve professions, different services and geographical locations. It also ensured that the survey design was directly informed and shaped by people using AHP services and AHPs themselves. Missing or 'bad' data meant that only 60% of the survey respondents were able to be matched with their health records, although there appears to be no discernible difference between those who could be matched and those who could not: using physiotherapy as an example (their return rate was over 90%) there is no difference between the numbers intervening at the 'precurve' stage in the full survey data or the smaller costed survey data – it is 26% in both datasets.

Results

A total of 13,448 completed surveys were returned to Strathclyde University which represents a return rate of 1.2 adjusted by 15% for those working solely in children and young people's services. Individual return rates varied between professions from 29% (diagnostic radiography) to >100% (podiatry). The average age of the participants was 67 years with approximately 30% over 85 years.

(Insert Figure 1)

Figure 1 shows the Scottish survey data and the Newcastle data (7) compared graphically although 24·3 % of the Scottish survey participants reported no problems with any ADL/IADL activity as measured by the LifeCurveTM. Inability to do heavy housework was the most prevalent problem in the survey at 62·7%, followed by cutting toenails (53·9%), shopping (51·4%), walking 400 yards (50·2%) and using steps (47·6%). These are the top five functional tasks in the LifeCurveTM and the survey data confirms the findings of the originators of the LifeCurveTM (6) in that loss of these five abilities occurs consistently at the beginning of functional loss.

Figure 1 also shows that the prevalence of functional difficulty reduces more rapidly after the fifth activity (heavy housework). Correlations between items were not strong (see supplemental information) with r^2 (coefficient of determination) values on average 0.18 (ranging from 0.02 to 0.42) indicating that all 15 items should be retained and that for people with temporary or long-term disability using AHP services the hierarchal loss of function seen in ageing adult populations may not apply. In other words, specific health conditions, such as neurological conditions, are likely to lead to condition specific functional deficits rather than the age-related loss described by the LifeCurveTM.

(Insert Table 1)

Table 1 shows the prevalence of participants' LifeCurveTM position (as numbers) broken down by age (in decades) and with the percentage by LifeCurveTM position and age in the final column and row respectively. From this it can be seen that survey participants fall broadly into three groups: those who have no functional difficulty as indicated by zero on the LifeCurveTM, those who have difficulty with heavy housework (the fifth stage) and those who are generally older and have more significant functional difficulties struggling with the tenth – thirteen stages. A few participants (2% and 5.1%) were unable to carry out the last two ADL/IADL on the LifeCurveTM i.e. most of the participants could wash their hands and face and eat and drink independently

(Insert Table 2)

Table 2 shows the average LifeCurve[™] position of participants seen by different professional groups. As might be expected radiographers and orthoptists tend to see people at the earlier stages (stages 0–3), whilst physiotherapists and occupational therapists in the main see people at later stages (stages 7–9). Although a number of physiotherapists were also found to intervene at the 'pre-curve' stage.

(Insert Table 3)

CHI numbers were available and linked to health records in 8,261 of the original 13,488 respondents (61.4%). The missing data was mostly due to the failure by staff to record the CHI number on the survey form. Table 3 shows the total costs for the 8,261 participants with matched health records for the full year of May 2016 – April 2017 alongside the number of people and the average cost per person.

(Insert Figure 2)

Figure 2 illustrates the cost per person per annum rises consistently across the LifeCurveTM. Thus 'pre-curve' and 'early curve' stages (1–4) account for 16%, 'mid-curve' stages (5–9) for 24% and 'late-curve' (10–15) for 60% of the total £54 million expenditure, which equates to an average spend per person of £6,850 ranging from £2,700 at 'pre-curve' to £ 12,330 at 'late-curve'. It should be remembered that these are not full health costs, for example they do not include primary care (other than prescription costs) nor do they include any social care costs or costs to the individual. Even so moving one position up the LifecurveTM would reduce costs by on average £640 pounds per person per annum according to our data. For our sample (n= 7877) this represents £5M in one year.

Discussion section

This paper set out to address a number of questions in relation to the Lifecurve[™] and age-related decline. The Lifecurve[™] as a conceptual framework for understanding functional decline, which is not necessarily purely age related, is generally understood by AHPs in professions providing reablement/rehabilitation. However, it is less understood by other AHPs, clinicians, health and care staff, people using services or policy makers. Public messages about ageing are frequently couched in negative terms about the 'burden' of old age and associated increasing health and social care costs (24). Understanding that ageing is malleable with functional decline compressed into the very end of later life (10) was found meaningful by all groups who took part in the survey. This indicates that the Lifecurve[™] could be a useful mechanism for engaging in conversation about how to achieve healthy ageing as defined by the World Health Organisation (5).

From the survey data it is clear that progression down the LifecurveTM was associated with increasing functional difficulty and health care costs. For some (particularly those in inpatient settings) functional decline will be linked to a short lived or acute episode of ill health. It may be that the pattern or order of decline differs in this group and additional analysis is required to investigate further. Specific mention should be made about survey returns from people receiving mental health AHP services as it can be seen that mental health costs contributed 35% of the total health care costs for 2016-7 but related to only $4 \cdot 1\%$ of the survey participants (n=339). This gives an annual cost per person in a mental health service of £87,000 compared to £10,000 on average for the total survey cohort. This pattern of spend highlights that this group can be considered as distinct and has therefore been excluded from further analysis here, but results will be subject to separate analysis and reported in a future publication.

A great deal of similarity between the Newcastle 85+ and Scottish survey findings is evident. The only major differences being less difficulty in cutting toe nails and more difficulty with both heavy and light housework in the Scottish survey data, and the lower average age. There were no equivalent "physical function problem free individuals" i.e. at the 'pre-curve' stage, reported in the original Newcastle 85+ Study (7) but inability to do heavy housework (stage 5) was the most prevalent functional difficulty in both studies. Scottish participants had greater

difficulty with this and were considerably younger (by an average 18 years) which is a larger age-related difference in performance than found when looking at life expectancy by region or socioeconomic status (25). It may, however, also be that a better definition of heavy housework is required to improve repeatability of findings in future surveys.

As the Scottish cohort were receiving AHP services, unlike the Newcastle cohort who were recruited through participating GP practices, this may have influenced the results in that people in receipt of AHP services are usually already experiencing a degree of functional difficulty for which they are seeking help. In this regard failure to perform heavy housework seems to be a seminal point for seeking and gaining assistance to prevent further functional decline. Overall, findings highlight that AHPs intervene at every LifecurveTM stage but with most activity undertaken at the later stages where functional improvement is possible but less likely to significantly change ageing trajectories. We can see that a relatively small number of respondents were positioned at the last two Lifecurve[™] stages, although only approximately 3.5% of the cohort stated they lived in a care facility (including sheltered housing). Interestingly the same 'grouping' of intervention across LifecurveTM stages (ie 'pre curve', 'mid curve' and 'late curve') was seen in this small group but, as one might anticipate, with higher numbers unable to transfer on/off a bed (stage 13). A quarter of survey participants were seen at the 'pre-curve' stage by AHPs who provide predominantly diagnostic and/or therapeutic interventions where preventative healthy ageing discussions are not typically held. For example, 26% of physiotherapists who took part in the survey were intervening at this stage and 44% of these were in musculoskeletal services (MSK). It seems there is scope to broaden intervention to include enabling active and healthy ageing activities, which may reverse or halt functional decline and reduce associated health care costs. Between 'mid- curve' at heavy housework (stage 5) and ability to do light housework or transfer on/off a toilet (stages 10 and 11) AHPs had least contact with survey participants. The cost consequence for people with this level of functional loss is evident in our cohort in that there is an average reduction in health care costs of £640 per person per annum per Lifecurve[™] stage. So it could be argued that moving someone from 'mid-curve' to 'early-curve' would potentially reduce an individual's annual health costs by £3,200, delay further functional decline and potentially change their ageing trajectory. For the relevant cohort in this paper this represents an annual reduction of over £9M. This data would seem to have some bearing on the kinds of conversations held across health and social care about positive and active ageing – including within AHP interventions.

As AHPs are part of the Scottish Governments' delivery arm around prevention and early intervention (2) and contribute across national policy areas such as Realistic Medicine which is promoting a personalised approach to care through shared decision making (26) and Adult Social Care Reform which is looking at outcomes-based approaches to commissioning (27), the survey findings provide opportunities to investigate different ways of working for AHPs. AILP's vision has been to refocus AHP contribution across this landscape around active and independent living by supporting individuals' personal outcomes (1) and as Scotland's new Public Health body develops to deliver the six public health priorities (28) and address current health inequalities, the survey findings provide a basis from which AHPs can consider their contribution. Gore et al (2018) suggest that using compression of functional decline as a framework for identifying the best intervention at each Lifecurve[™] stage will deliver maximum benefits for both people receiving and providing services (6).

Healthy ageing has been framed by WHO as the functional ability required for wellbeing which includes both an individual's intrinsic capacity and their environment (5). To support improved functional ability, the survey

findings point to a need for change in how AHPs intervene across Lifecurve[™] stages, especially at 'pre-curve' and early stages. In addition, at 'mid curve' stages we need to find other ways of having a conversation about functional decline and supporting people to compress this. Given most intervention occurred at the 'late-curve' stage, one might argue this is too late for prevention, however, this will depend on the level of prevention being undertaken (29) and ignores the impact of planning ahead (30,31).

We believe that we must use all suitable points of contact within our communities to help drive the message that functional decline in later life is not an inevitability, to publicise the research to support this assertion, to show that fitness in later life can be the rule not the exception, to provide means by which people can monitor for themselves their LifecurveTM status and to signpost them to community, commercial and statutory resources and opportunities that are appropriate for preventative health and maintaining optimum physical function. AHPs can have a significant role to play in the paradigm shift which will see older people viewed as assets in their community, where investing in their wellbeing brings societal "participation, consumption and social cohesion" (5). We all want extended quality of life years, not merely longer life and changing the AHP focus and contribution to address functional decline at earlier stages has potential to save health and social care costs and presents a sustainable way to support and harness the potential of Scotland's older people.

Footnote: Please note that the term LifeCurveTM is the unregistered trademark of ADL Smartcare Ltd.

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Table 1 AILP Survey: prevalence of inability to do certain functional activities compared in ALIP survey participants (n=13,448) compared to the Newcastle 85+ study (n=839, Kingston et al 2012).

LifeCurve [™] position	10	20	30	40	50	60	70	80	90	100		LifeCurve™ Occurance %
0	105	90	142	168	179	231	255	207	150	103	16	24.3
1	15	6	16	20	9	21	29	39	28	14	0	2.9
2	5	5	5	6	5	5	9	8	9	2	2 (0.9
3	6	3	9	6	7	9	10	11	9	4	1	1.1
4	8	3	7	16	15	15	21	30	17	7	1	2.1
5	55	59	66	80	76	82	98	136	126	79	16	12.9
6	15	14	21	16	14	26	34	38	31	15	2	3.3
7	16	17	23	16	13	29	36	40	37	20	3	3.7
8	13	5	22	13	21	23	21	30	40	17	2	3-1
9	2	7	3	7	8	10	11	10	12	1	1	1.1
10	34	28	39	42	43	52	57	79	109	54	3 8	8.0
11	27	23	43	39	41	45	59	82	84	44	5	7.3
12	41	34	27	42	57	60	66	64	67	45	13	7.6
13	79	47	81	59	90	154	138	171	172	88	18	16-2
14	6	7	12	8	12	9	21	22	24	10	4	2.0
15	23	20	35	20	33	44	51	46	39	31	3 5	5-1
	6.6	5.4	8.1	8.2	9.2	12.0	13.5	14.9	14.1	7.9	1.3	

Table 1: LifeCurve[™] position versus participant age in decades with the most prevalent responses shaded (n=13,448).

Profession	Average LifeCurve [™] position				
Radiographer (Therapeutic)	2.1				
Radiographer (Diagnostic)	2.6				
Orthoptist	3.5				
Dietician	5.4				
Podiatrist	5.6				
Prosthetist/Orthotist	6.0				
Arts Therapist	6.3				
Paramedic	6.4				
Physiotherapist	6.6				
Speech and Language Therapist	7.4				
Assistant Practitioner	7.6				
Occupational Therapist	8.8				

Table 2: Average LifeCurve[™] position by profession (n=13,448).

Health care type	Cost (£)	Users (N)	Cost per User (£)
Acute in-patient and day admissions	48,466,889	4,103	11,813
Maternity in-patient and day admissions	125,421	35	3,583
Mental health in-patient and day admissions	29,663,218	339	87,502
Out-patient attendances	1,188,638	4,117	289
Accident and Emergency attendances	812,108	3,379	240
Primary care prescription costs (£10/item) *	5,085,000	7,999	636
Total Cost	85,341,274	8,261	10,331

*Prescription cost based on NHS England estimate of £10/prescription

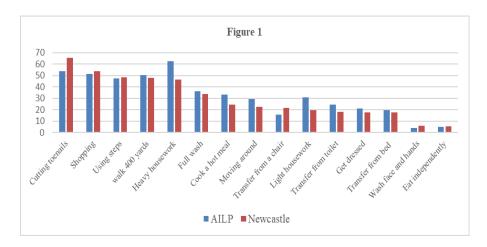


Figure 1 AILP AHP Survey: prevalence of inability to do certain functional activities as a percentage compared to the Newcastle 85+ study (Kingston et al 2012).

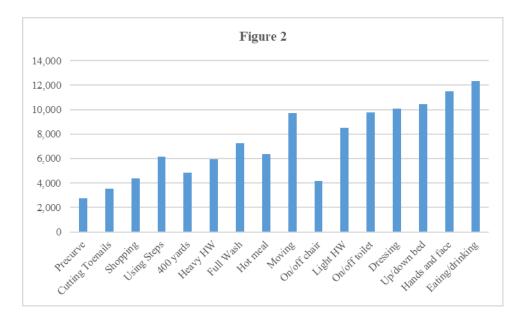


Figure 2: NHS costs per LifeCurve[™] position per year in pounds. (n=7887) with maternity (n=35) and mental health (n=339) users removed.