THEORY BASED EVALUATION OF LONG TERM CONDITIONS AND MACMILLAN BENEFIT ADVICE SERVICE
in
Queen Elizabeth University Hospital, Glasgow

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EXECUTIVE SUMMARY

BACKGROUND

Integration of health and social care is one of Scotland's major programmes of reform. At its heart it is about ensuring that those who use public services get the right care and support whatever their needs, at any point in their care journey. Welfare benefit services are one component of social care support and can play an important role reducing patient's stress and anxiety. The Macmillan Welfare Benefits service was originally set up in 2008 to provide advice for cancer patients. However, it soon became evident that there was a need for such a service for all patients who have a long term conditions that may result in financial hardship. The service expanded, and is now available in Queen Elizabeth University Hospital (formally Southern General Hospital). One of the flagship services in the hospital is in the spinal unit where members of the Southern General (SG) Financial Inclusion Service visit patients on the ward and can provide early support with welfare benefit claims and other sources of funding for financial issues (e.g. the Macmillan fund).

METHODS

This evaluation was undertaken to determine whether the service delivered in the Queen Elizabeth University Hospital and the spinal unit achieved its aims and objectives. We collected and analyzed three types of data: 1) quantitative data on clients (e.g. how many were seen, their background, and how much funding they received) in the period January 2014-October 2015; 2) qualitative interviews with key stakeholders; 3) existing research, reports and case studies provided to us by Macmillan/Glasgow City Council.

QUANTITATIVE RESULTS

From the research we undertook, it is indisputable that many patients at Queen Elizabeth University Hospital/Southern General Hospital have received financial support from the SG Financial Inclusion Service. They included some of the most financially vulnerable patients in our health care system. Key findings include:
The service is reaching patients who have a significant need for financial advice and support
The evaluation data (which did not include referrals to DWP and other local authorities) found that:

- 1,567 clients had 2,013 applications for funding during the period January 2014-October 15
- Only 3% were currently working, with 45% being unable to work due to ill health. This statistic on its own suggests that the service is addressing a population group with a significant need for financial advice and support
- Over two thirds of the clients lived in social housing (twice the national average) and over 50% of people came from the most socially and economically deprived areas. Data sample used of 793 clients in this report did not include referrals to DWP and other local authorities).
- Financial outcomes all applications totalled £2,352,487.98.

Most applications for funding are processed and awarded within 3 months

- 1579 (77%) of the applications resulted in the client receiving financial support.
- Over 50% of cases received their award in under six weeks and 80% within 3 months

Most awards are worth over £1,000 per client

- Successful financial support ranged from £59 up to £66,000.
- The median amount of financial support awarded per application was around £1,120

Clients received support from over 35 different funding sources, many of which they might not have known about without the service

- Clients received financial support from 37 different funding sources
- The largest contributor, with more than 30% of awards, was Macmillan grants followed by Personal Independence Payments (PIP, 16.7%) and Attendance Allowance (14.5%).
- Other awards ranging from £2000 upwards included carer's allowance, Disability Living Allowance, Employment and Support Allowance and Housing Benefit/Local Housing Allowance.

QUALITATIVE RESULTS

Our qualitative and document research demonstrated that:

- A partnership approach to working is important. For example, the Department for Work and Pensions (DWP) are a vital partner and referrals are made directly to them, which also resulted in a streamlined/fast track verification process
- There is a housing professional in the team and money and debt officer
- The partnership approach can contribute to the prevention of homelessness as well as the provision of financial benefits.
- There are several ways in which the service can have an impact. It can improve financial, housing and health outcomes (decreased stress and anxiety) for clients and it can benefit the wider NHS (through reducing bed days, clinical time).
- It is important to have Welfare Rights Officers visit the wards, especially on spinal unit (where people are not able to attend face-to-face assessment for their applications). Having a member of the Southern General (SG) Financial Inclusion Service on the ward was seen as being a highly effective way of reducing such delays in discharge.
- It is important to have a visible presence on the ward or in the hospital. It can help 'change the mindset'of clinical staff – helping them to realize that working together on all aspects of a patient's life could improve outcomes and quality of life.
- There are some 'unintended' or unanticipated outcomes. For example, there were more issues surrounding housing and homelessness than anticipated. Also, some patients were anxious when approached initially by someone from Macmillan, as they associated the organization with cancer, and not wider health conditions.

CONCLUSIONS

The quantitative data demonstrates the service has achieved its aims and objectives of providing early intervention and support to prevent hardship, poverty and exclusion for people in the South of Glasgow. The service also reaches and impacts on those people who are most in need. The qualitative data aids in explaining the ways in which the service can be incorporated successfully into a clinical setting and enable multiple partners to work together for the health of patients and their families.

This is a service that has demonstrated that it can work within a hospital setting to reduce health inequalities and help those in most financial need. It is an exciting opportunity for the NHS in Glasgow to be at the forefront of an innovative model of integrated service that could be scaled up to other parts of the NHS.

RECOMMENDATIONS

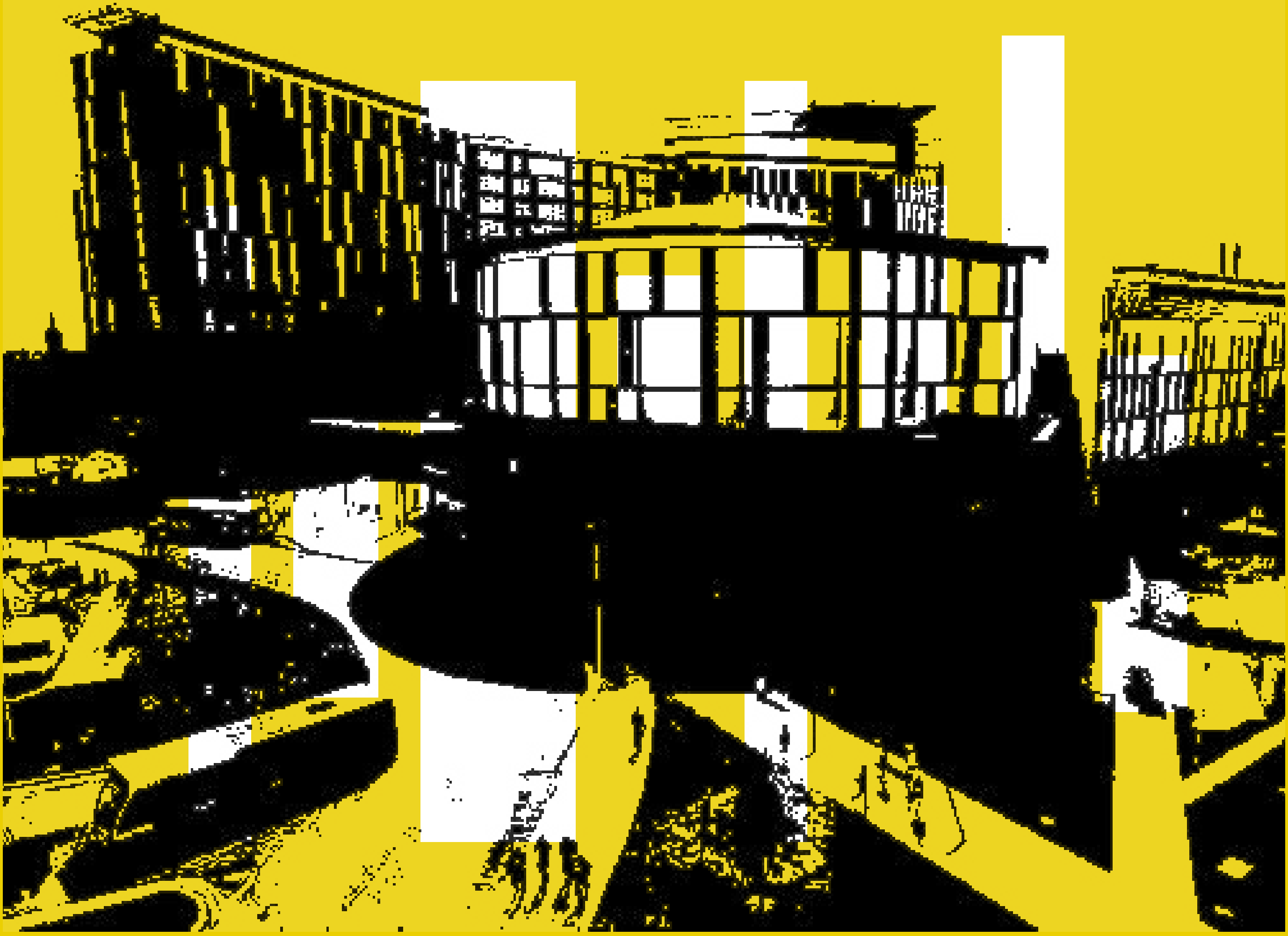
Funders and the NHS

- The service should be funded and, if possible, embedded as part of a core service provided to patients with long term conditions.

Service providers

- Future strategy and planning of the service should include:
  - consideration of the 'branding' of Macmillan (currently some people associate it only with cancer which can be confusing)
  - further emphasis and reorientation on social housing and homelessness.
- Further research in this area is needed to understand how clients view the service and the impact it has on their lives.
- The service should develop a 'Standard Operating Procedure' (SOP) document that all people entering data into the database follow and if possible build rules into the database to standardise the format of each data field.

BACKGROUND



Employment and income are key factors that affect our health, and even small changes in these factors may be important for people living on low incomes and dependent on welfare[1]. It is increasingly recognised that people with long term conditions such as cancer or heart disease can face considerable financial hardship[2 3 4], resulting from loss of income for example. There is also an increasing body of research evidence that once a clinical diagnosis has been given, many people worry about the impacts of their diagnosis on their finances. Integration of health and social care is one of Scotland's major programmes of reform. At its heart it is about ensuring that those who use services get the right care and support whatever their needs, at any point in their care journey[5]. One of the aims of the welfare benefits service is to provide financial advice and support to the patient at a time they need it most (often shortly after diagnosis). *There is robust research evidence that welfare rights advice delivered in healthcare settings results in financial benefits*[6].

The Macmillan benefits service in Glasgow was developed initially through a partnership between Glasgow City Council and Macmillan Cancer Support in November 2008. The rationale for the service was that if people get dedicated support with welfare benefits and housing-type issues after a cancer diagnosis, then this will allow them to concentrate on their cancer treatment, rather than worrying about their financial circumstances. It was expanded in February 2010 to cover other long term conditions by bringing together seven other agencies working in partnership, including: Glasgow City Council; Chest, Heart and Stroke Scotland; Glasgow Housing Association; NHS Greater Glasgow & Clyde; The Pensions Service; Jobcentre Plus; and Glasgow's Advice and Information Network. This service supports clients to maximise income; increase benefit uptake; and reduce debt. It also provides help with financial problems[7].

Within the Southern General Hospital (now Queen Elizabeth University Hospital), the SG Financial Inclusion Service was established to support patients and their families and the general community in the Southside of Glasgow. The aim of the service is to reduce health inequalities by providing early intervention and support to prevent hardship, poverty and exclusion for people in the South of Glasgow experiencing ill health, particularly through guidance in welfare benefits applications and supporting housing needs. The SG Financial Inclusion Service began working within the Spinal Unit in March 2014. It was developed with a view to reducing the length of time patients would have to wait on a Personal Independent Payment (PIP) decision and award. The average wait for an award for patients was 30 weeks and this could have huge implications for patients who required PIP to be in place to facilitate their care plans at home and could often mean delayed discharge[8]. This evaluation was designed[9] to help inform decision makers as to whether to further fund the service.

Evaluation involves making a judgement as to how successful (or otherwise) a project has been, with success commonly being measured as the extent to which the project has met its original objectives. Both the "process" (activities) and "outcomes" (what is produced, for example in terms of changes in the health of those targeted by the project) can be ... evaluated.' World Health Organization (2014)[10].
There are many types of evaluation that are possible to determine the impact of a service. This is a theory driven evaluation which uses theory (how and why) to understand the extent to which the programme has achieved its aims, and the impact that can be attributed to the service. Evaluation of plausibility and strength of the association between the service and the outcomes can provide powerful evidence. Findings that demonstrating changes in the various links in the causal pathway (e.g. number of patients receiving financial benefits before they leave hospital) can provide strong plausibility support that programme impact (e.g. reductions in delayed discharge) has occurred[11].

To provide a 'true estimate' of the effectiveness of the SG Financial Inclusion Service, we would have needed to have a control or comparison group, and preferably undertake a randomised controlled trial (RCT). However, a review of studies of welfare benefit services (including RCTs) has already found that such services can lead to financial gain for clients[12]. As effectiveness of such services has already been established it is not always necessary to have further outcome evaluations. What is perhaps more important is in understanding how a service is implemented and whether it is able to achieve its aims in the setting in which it is implemented.

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[8] LTC/Macmillan Queen Elizabeth University Hospital & Spinal Unit Report, February 2016

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[12] Adams J, White M, Moffatt S, Howel D, and Mackintosh J: A systematic review of the health, social and financial impacts of welfare rights advice delivered in healthcare settings. BMC Public Health 2006, 6:81.

AIMS & OBJECTIVES

The overall aim of the evaluation was to explore the impact of having a dedicated welfare benefits service within the Southern General Hospital (now Queen Elizabeth University Hospital). Within this overall aim there were a number of objectives which included:

1. Describing the type of clients who use the service and the reach of the service (s)
2. Identifying the impact of the Benefits Service in terms of:
    - Financial awards for clients
    - The length of hospital stays (for the spinal unit)
    - Housing provision
3. Identifying the impact of early intervention provided by the Benefits Service – particularly in relation to the in-hospital service in the Spinal Unit
4. Providing an understanding of the intended and unintended impacts of the Benefits Service for the key partners
5. Identifying any unmet needs from the Benefits Service

METHODS

This evaluation used a variety of data sources to explore the impact of the Benefit Service. It was undertaken in two parts: evaluation of the Queen Elizabeth University Hospital/Southern General service (and the Spinal Unit in particular). The data we collected included:

1. Qualitative interviews with key stakeholders
2. Quantitative data from the Macmillan database.
3. Existing reports and case studies

For the evaluation of the specific service in the Spinal Unit, we developed a logic model (Figure 1) to outline the activities undertaken by the Welfare Benefits Team and the intended and expected outcomes. It also demonstrates the underlying programme theory (i.e. how and why the Benefits Service impacts on outcomes). The qualitative and case study data we collected enabled us to evaluate whether the service was successful in achieving its aims and whether it could have plausibly caused some of the changes in outcomes (e.g. decreases in time taken for an application to be successful).

For this evaluation we brought together these different sources of data and the related analyses, which enabled a greater understanding of the effectiveness and impact of the services. As we were unable to use an experimental design to evaluate effectiveness, we were not be able to determine how effective the service is compared to not having a service, nor were we able to fully establish whether any effects are wholly due to the service, or could be due to external causes (e.g. similar services). However, we evaluate the plausibility of the service causing the impacts or outcomes.

Quantitative study

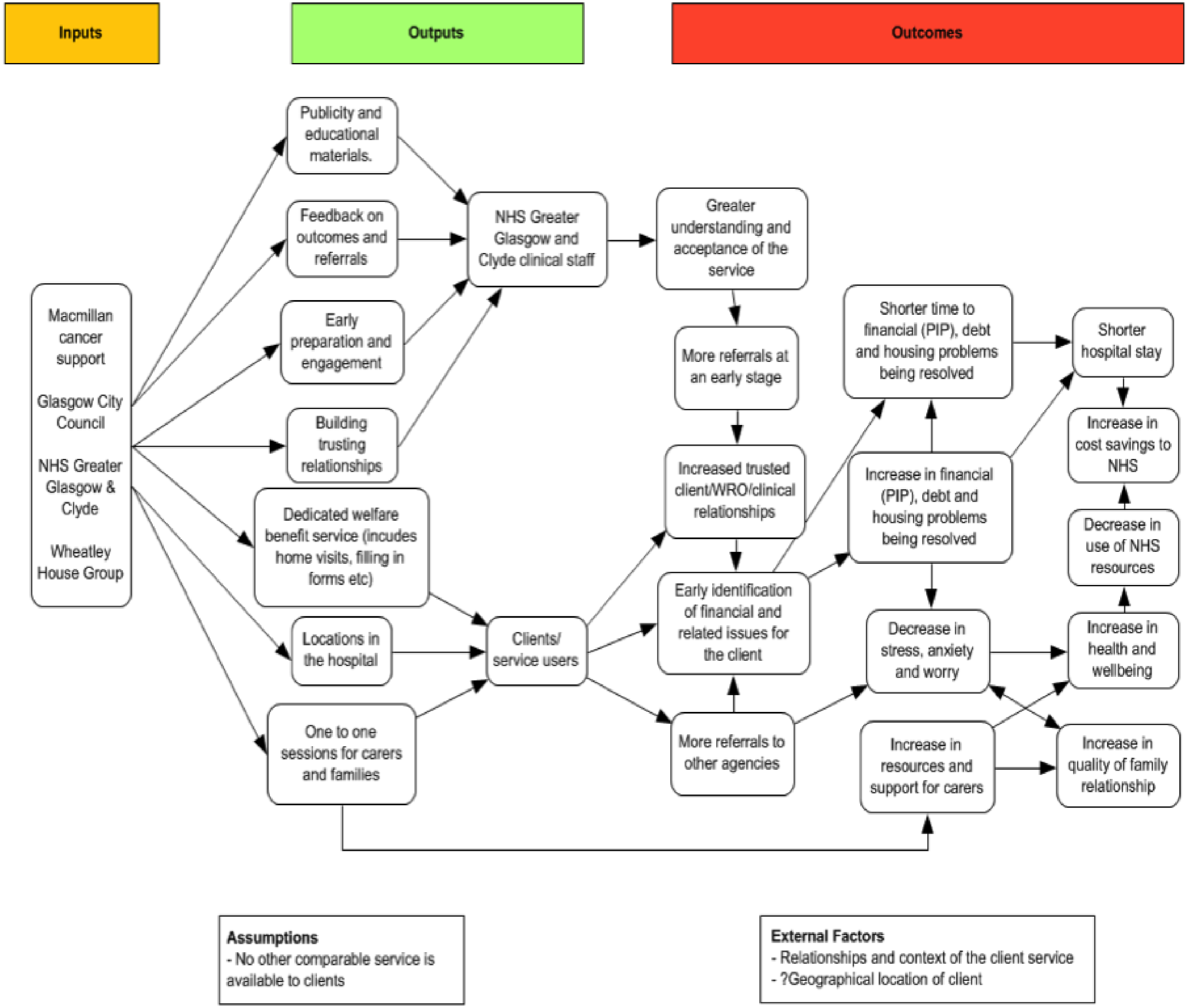
Quantitative methods were used to answer a number of questions regarding the Benefits Service as follows.

1. How many clients have been seen by the service, and where do the clients referred from?
2. What is the client base of the service (e.g. sex, age, socioeconomic status, primary health condition)?
3. What is the monetary value of benefits sourced for clients through the service?
4. Has the time taken for clients to receive benefits been reduced?

ANALYSES

These questions have been formulated to use the data available from Macmillan (which did not include data on referrals to DWP and other local authorities) and where possible compare it with data available from Information Services Division Scotland or other sources (e.g. Citizens Advice Bureau). At best, these data are available at the level of Health Board (or Community Health Board), which limited some of the comparisons. TR and AJW carried out the analyses. They carried out descriptive explorations of the data initially and then, where appropriate, extend to statistical modeling (single and multivariable regression models). It was not possible to answer all the evaluation questions through analysis of quantitative data. Some of the key findings and insights can come from qualitative interviews.

Figure 1. Logic Model and Theory of Change for the benefits Service in the Spinal Unit



Assumptions
- No other comparable service is available to clients

External Factors
- Relationships and context of the client service
- ?Geographical location of client

Qualitative study

The aim of this part of the evaluation was to gain insights from key stakeholders and to how they experiences and views of the service worked (e.g. was it meeting it aims and goals).

We interviewed eight key stakeholders from a range of organisations/positions including:

- Long Term Condition Service
- Wheatley Housing group
- NHS
- NHS health improvement
- Macmillan
- DWP

SAMPLING AND RECRUITMENT

The sample of key stakeholders was decided upon in discussion with Glasgow City Council and Macmillan – it included people who are involved in one way or another with all the activities described in the logic model or other activities delivered by the welfare benefits staff – from those delivering the intervention, to those who work with or alongside them (e.g. health professionals. Due to the limited time and resources available for the evaluation we did not interview clients who received the advice and support from the welfare benefits service. However, we did look at case reports and other documents that shed light on the impact on clients. Once the key informants were identified, researcher KL sent an email and participant information sheet. If they agree to participate, KL sent them a consent form to fill in before the interview took place.

DATA COLLECTION

The interviews took place either face-to-face at a mutually convenient location, or over the phone. Whilst face-to-face interviews are preferable, it was not always be possible to talk to people (e.g. clinicians, hospital staff) during their work hours. The interviews were semi-structured and a topic guide was used.

ETHICS

As this was a service evaluation and does not involve patients, NHS ethics was not required. However, level 2 ethics was approved by the University of Edinburgh, Centre for Population Health Sciences Ethics Committee.

INFORMED CONSENT

Participants were provided with an information sheet and received a briefing before their interview takes place (see under sampling and recruitment). They were asked to complete a consent form prior to the interviews taking place.

DATA MANAGEMENT

All interviews were digitally recorded and transcribed and transcripts were anonymised. However, as these are key stakeholder interviews it was not wholly possible to maintain full confidentiality in the report. This was explained in the information sheet, and also referred to in the consent form. Written data, including consent forms, and computer records will be kept for five years after the end of the study, after which they will be shredded and deleted.

ANALYSIS OF QUALITATIVE DATA

The data were analyzed thematically. Initial codes were developed and discussed between two team members (RJ and KL) and a coding manual developed. Themes were developed from the codes and reflected the theory of change outlined in the logic model (for the spinal unit) and other activities that are undertaken by various members of staff leading to the changes that are expected in the spinal unit and the wider welfare benefits service. The analysis also focused on stakeholder views of how and why the service is effective/not effective.

Documentary analysis

We received reports and case studies that had been primarily written or collated by Glasgow City Council or Macmillan. We also received letters of support from clinical staff who saw a benefit from the service. We used a similar approach to the qualitative data; codes were developed to thematically analyse the content of the documents.

RESULTS

For the following analyses, participation in the Southern General Project has been derived from having 'funding source' in the database listed as 'Improving the Cancer Journey (SGP)' or 'Southern General Project'.

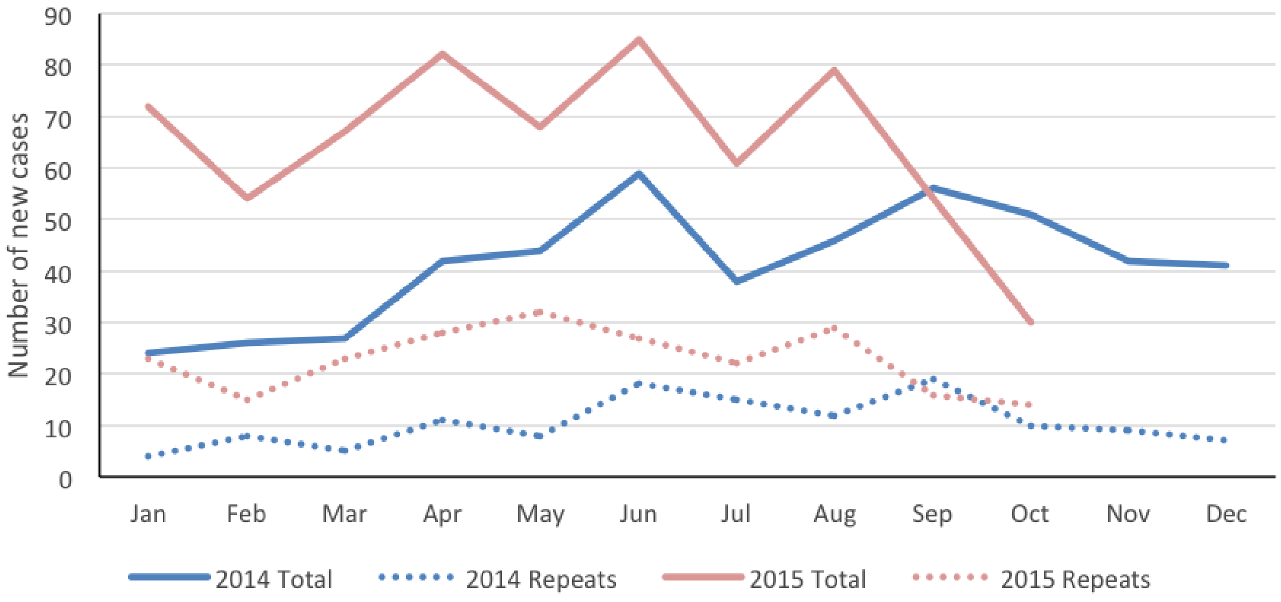
SERVICE USE

Between January 2014 and October 2015 there were 793 unique clients handled as 1,148 cases. 550 (69.4%) clients only resulted in a single case being highlighted (e.g. one case open date); the highest number of cases per client was 5. Each case may have resulted in applications to more than one funding source. It is not possible to identify much of a pattern in the number of cases each month at this stage (Figure 1). The October 2015 decline is most likely the result of all available data not having been collected by this time.

Table 1 – Number of cases opened each month (number of repeat clients)

	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEPT	OCT	NOV	DEC
2014	24	26	27	42	44	59	38	46	56	51	42	41
	(4)	(8)	(5)	(11)	(8)	(18)	(15)	(12)	(19)	(10)	(9)	(7)
2015	72	54	67	82	68	85	61	79	54	30	-	-
	(23)	(15)	(23)	(28)	(32)	(27)	(22)	(29)	(16)	(14)		

Figure 2 – Number of cases opened each month



CLIENT DEMOGRAPHICS

Table 2 provides details of the demographic make-up of the clients seen between January 2014 and October 2015 in comparison to the Glasgow population. There were slightly more males than females (54% vs. 47%) referred to the service and the mean age was 61 years, with 54% being over 60 years of age. Significantly, only 3% were currently working, with 45% being unable to work due to ill health. This statistic on its own suggests that there the service is addressing a population group with a significant need for financial advice and support. Additionally over two thirds of the clients lived in social housing which is twice the national average and over 50% of people came from the most deprived SIMD quintile (the same as the national average).

Table 2 – Client profile (all data based on their first case)

		Summary statistic	Missing Data	Glasgow Population**
Total		793 (100%)		593,245 (100%)
Sex	Male	424 (53.5%)	0 (0.0%)	286,076 (48.2%)
	Female	369 (46.5%)		307,169 (51.8%)
Age	Means	61.6±14.6	1 (<0.1%)	
	0-39 years	64 (8.1%)		326,601 (55.1%)
	40-59 years	281 (35.4%)		156,129 (26.3%)
	60-79 years	367 (46.3%)		88,106 (14.9%)
	80+ years	80 (10.1%)		22,409 (3.8%)
Ethnicity*	White	767 (96.7%)	3 (0.4%)	524,561 (88.4%)
	Asian or Asian British	16 (2.0%)		47,758 (8.0%)
	Any other ethnic group	7 (0.9%)		20,926 (5.3%)
Economic activity#	Employed	30 (3.8%)	0	260,460 (52.3%)
	Retired	384 (48.4%)		88,730 (17.8%)
	Unable to work due to ill health	354 (44.6%)		73,052 (14.7%)
	Other	25 (1.6%)		75.376 (15.1%)
Living in social housing		538 (67.8%)	-†	104,811 (36.7%) $

Cont..

Quintile of SIMD 2012	1 (most deprived)	398 (50.2%)	18 (2.3%)	287,794 (48.0%)
	2	156 (19.7%)		111,372 (18.6%)
	3	100 (12.6%)		77,921 (13.0%)
	4	74 (9.3%)		69,689 (11.6%)
	5 (least deprived)	47 (5.9%)		52,874 (8.8%)
Decile of SIMD 2012	1 (most deprived)	297 (37.5%)	18 (2.3%)	197,854 (33.0%)
	2	101 (12.7%)		89,940 (15.0%)
	3	92 (11.6%)		57,450 (9.6%)
	4	64 (8.1%)		53,922 (9.0%)
	5	52 (6.6%)		39,096 (6.5%)
	6	48 (6.1%)		38,825 (4.8%)
	7	34 (4.3%)		28,844 (4.8%)
	8	40 (5.0%)		40,845 (6.8%)
	9	27 (3.4%)		32,051 (5.3%)
	10 (least deprived	20 (2.5%)		20,823 (3.5%)

SD; standard deviation, SIMD; Scottish Index of Multiple Deprivation based on postcode;*Due to small cell numbers those categories of ethnicity with less than 10 people (Chinese, Asian or Asian British and Mixed/Dual background) have been incorporated into 'Any other ethnic group'; ** All Data from the 2011 Census of Glasgow City local authority area and retrieved from www.ScotlandCensus.gov.uk (Standard Outputs). Exceptions are data from SIMD made available from SIMD 2012 and National Records of Scotland, based on data from 2014 and retrieved from www.UnderstandingGlasgow.com; # Economic activity for Glasgow City population is only based on those 16 and over (n=497,618).; ǂ0 records missing, 173 not applicable and 82 not specified; $ Percentage is based on number of households (n=285,693)

CLIENT DIAGNOSIS

Table 3 lists the diagnoses of clients and their relative frequencies (percentage). The majority of clients had a cancer diagnosis and the most common sites were breast and the respiratory/ intrathoracic organs. Data from a report by Glasgow City Council for the Spinal unit suggests that 86 of the total clients were from the spinal unit.

Table 3– Client diagnosis by chapter of the International Classification of Diseases version 10 (ICD-10)

Diagnosis	Frequency	Percent of all diseases	Percent of all cancers	Glasgow Incidence 2013*	Percent of all cancers
Chapter II – Neoplasms**	488	61.5%	100.0%	8,918	100%
C00-C14 - Malignant neoplasms of lip, oral cavity and pharynx	28	3.5%	5.7%	217	2.40%
C15-C26 - Malignant neoplasms of digestive organs	79	10.0%	16.2%	1477	16.60%
C30-C39 - Malignant neoplasms of respiratory and intrathoracic organs	107	13.5%	21.9%	1403	15.70%
C50 - Malignant neoplasm of breast	60	7.6%	12.3%	969	10.90%
C51-C58 - Malignant neoplasms of female genital organs	30	3.8%	6.1%	348	3.90%
C60-C63 - Malignant neoplasms of male genital organs	35	4.4%	7.2%	624	7.00%
C64-C68 - Malignant neoplasms of urinary tract	16	2.0%	3.3%	359	4.00%
C69-C75 - Malignant neoplasms of eye, brain and other parts of central nervous system, or thyroid and other endocrine glands	22	2.8%	4.5%	169	1.90%
C76-C80 - Malignant neoplasms of ill-defined, secondary and unspecified sites	36	4.5%	7.4%	209	2.30%
C81-C96 - Malignant neoplasms, stated or presumed to be primary, of lymphoid, haematopoietic and related tissue	23	2.9%	4.7%	468	5.20%
Cancer could not be categorised	38	4.8%	7.8%		
Chapter V – Mental and behavioural disorders	16	2.0%			
Chapter VI – Diseases of the nervous system	17	2.1%			
Chapter IX – Diseases of the circulatory system	87	11.0%			
Chapter X – Diseases of the respiratory system	75	9.5%			
Chapter XIX – Injury, poisoning and certain other consequences of external causes	79	10.0%			
Other#	14	1.8%			

*Based on recorded cancer diagnoses within NHS Greater Glasgow and Clyde, 2013, taken from the Scottish Cancer Registry and provided by ISD Scotland (Ref: IR2016-00191)**Percentages of the individual section of Chapter II have been have been calculated from the total for Chapter II. #Others include diagnoses from Chapter I - Certain infectious and parasitic diseases, Chapter II – Neoplasms; C40-C41 - Malignant neoplasms of bone and articular cartilage, C43-C44 - Melanoma and other malignant neoplasms of skin, C45-C49 - Malignant neoplasms of mesothelial and soft tissue, Chapter III - Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism, Chapter IV – Endocrine, nutritional and metabolic diseases, Chapter VII - Diseases of the eye and adnexa, Chapter VIII - Diseases of the ear and mastoid process. Chapter XI – Diseases of the digestive system, Chapter XII - Diseases of the skin and subcutaneous tissue, Chapter XIII – Diseases of the musculoskeletal system and connective tissue, Chapter XIV – Diseases of the genitourinary system and Chapter XXI – Factors influencing health status and contact with health services.

FINANCIAL SUPPORT RECEIVED

The 1567 clients resulted in 2,013 applications for funding of which 1579 (77%) resulted in the client receiving financial support which was recorded in the dataset. Successful financial support appears to range from £58.98 up to £66,000 (Figure 2). The median financial support awarded per application was £1,120.60 and Table 5 summarises the financial support awards across all financial levels, with around 50% receiving less than £1,000.

Figure 3 – Range of quantities of financial support received and number of cases

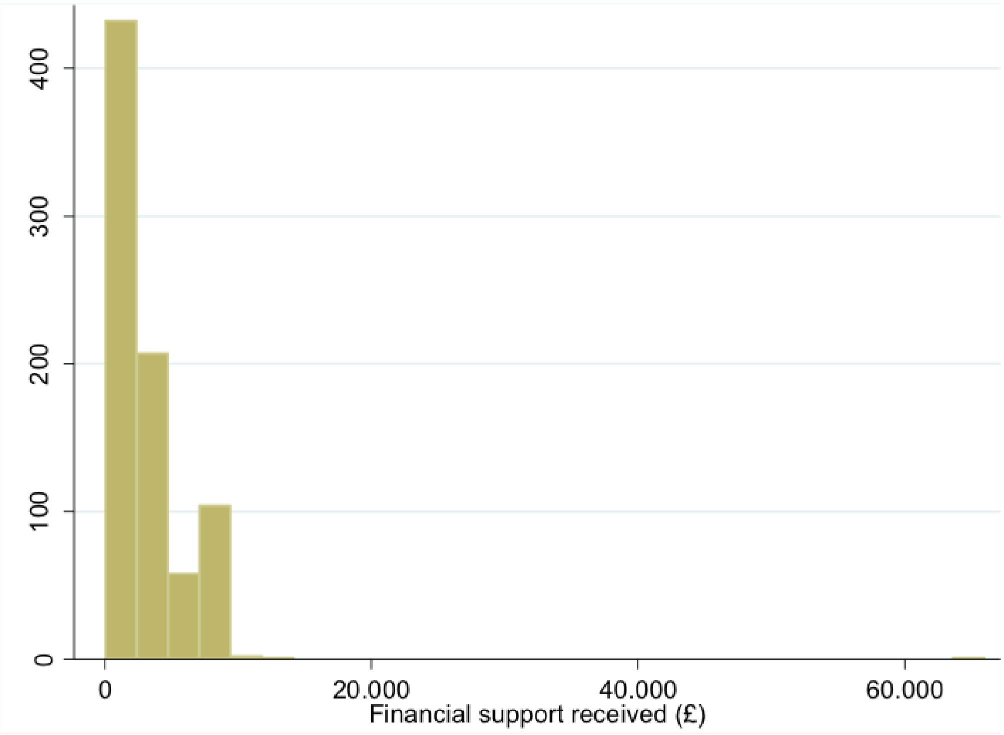


Table 5 – Financial support awarded per successful application

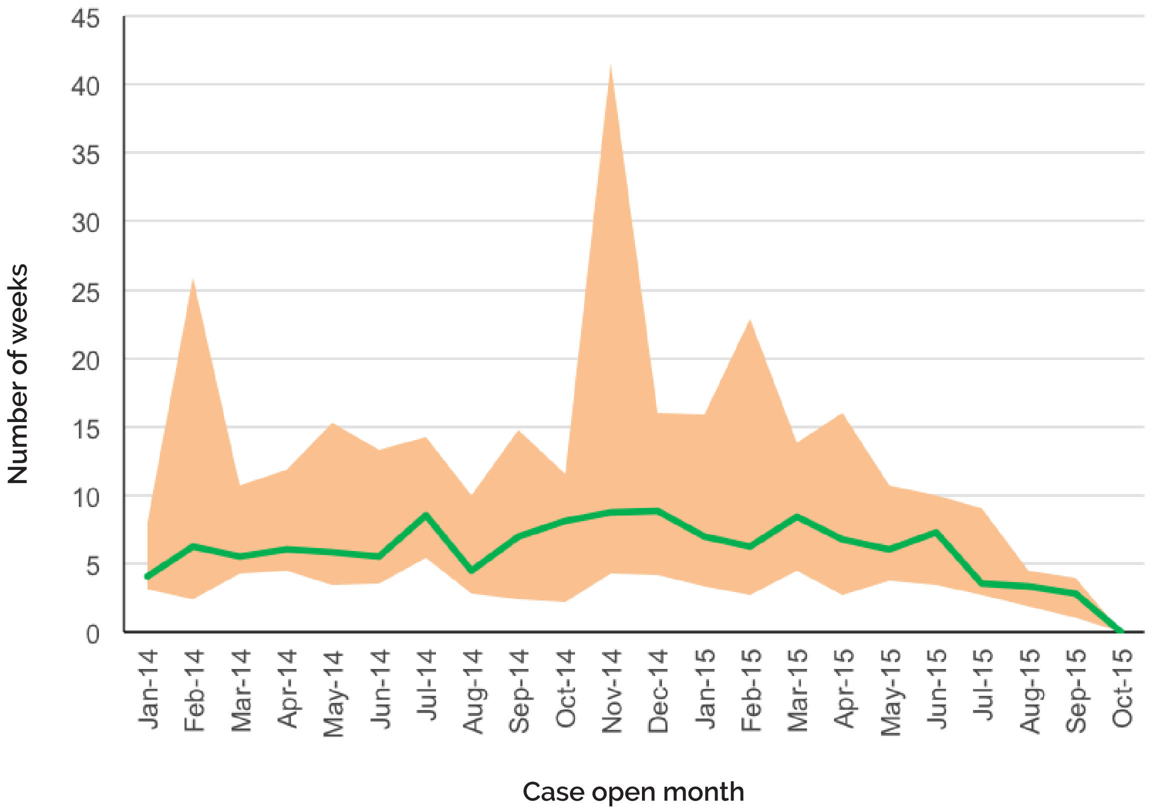
Financial support awarded	Frequency	Percent
<£300	136	16.9%
£300 - <£400	180	22.4%
£400 - <£1,000	82	10.2%
£1,000 - <£4,000	119	14.8%
£4,000 - <£5,000	123	15.3%
≥£5,000	165	20.5%

Table 6 – Time to financial gain per successful application

Time to award	Frequency	Percent
Within 6 weeks	329	51.3%
6 weeks to 3 months	169	26.4%
3-6 months	89	13.9%
6 months to 1 year	39	6.1%
More than 1 year	15	2.3%

Figure 3 illustrates the change in time to award across the period studied. We were not able to identify any marked increase or decrease in time to award. The reduction in time to award across July-October 2015 is probably due to the fact that sufficient time had not passed for the longer awards to be received, this is reflected by the smaller number of awards.

Figure 4 – Median time to financial award by case open month (interquartile range shaded)



Of the clients to receive financial support, data on the source of the support was missing for 3 (0.4%). Clients received financial support from 37 different funding sources (Table 7). The largest contributor with more than 30% of awards were Macmillan grants, followed by attendance allowance and Personal Independence Payments (PIP, 16.7%) and attendance allowance (14.5%). Table 7 also contains summaries of the time to award and quantity of financial support from reach funding source. Macmillan grants were received, on average, within around 4 weeks; PIP around 12 weeks and attendance allowance around 5 weeks. PIP was the highest, on average, awarding approximately £7,000. Other significant awards ranging from £2000 upwards included Carer's Allowance, Disability Living Allowance, Employment and Support Allowance and Housing Benefit/Local Housing Allowance. We have not been able to obtain data to compare this data to Glasgow/national averages, so cannot comment if the service is ensuring speedier awards. However, given the longer time it typically takes for clients to receive the larger, social security type benefits, the smaller awards may be an important safety net for many people while they await awards such as PIP and DLA.

Of the 793 clients who engaged with the service between January 2014 and October 2015, only 573 (72.3%) are recorded as being awarded financial support. The amount awarded per client (as opposed to per application) ranged from £64.76 to £82,785.60. Table 8 summarises the variation in financial support received per client. The median financial support received per client was £3,952 with interquartile range £250 to £5,853. A third received less than £500, while around a quarter received £5,000 or more.

Table 7 – Funding source, time to award and quantity of financial support

Funding Source	Frequency (%)	Median time to award in weeks (IQR)*	Median financial support (IQR)*
Attendance Allowance	116 (14.5%)	5.6 (2.4, 12.0)	£4,228 (£4,228, £4,280)
Chest, Health and Stroke Scotland grant	46 (5.7%)	11.1 (6.9, 14.4)	£250 (£200, £300)
Council Tax Reduction	13 (1.6%)	3.1 (2.0, 15.9)	£715 (£582, £879)
Disability Living Allowance (DLA)#	61 (7.6%)	10.9 (5.1, 19.0)	£4,228 (£3,999, £6,890)
Employment and Support Allowance (ESA)‡	50 (6.2%)	9.1 (2.8, 13.4)	£5,386 (£3,765, £6,503)
Housing Benefit / Local Housing Allowance	13 (1.6%)	4.7 (3.0, 7.0)	£3,142 (£1,642, £4,740)
Macmillan grant	266 (33.2%)	4.0 (2.7, 6.1)	£300 (£300, £350)
Personal Independence Payment (PIP)‡	134 (16.7%)	12.7 (6.3, 23.0)	£7,179 (£5,413, £7,267)
Scottish Welfare Fund	36 (4.5%)	3.7 (2.1, 6.1)	£229 (£205, £365)
Other§	68 (2.0%)	10.0 (3.7, 16.7)	£1,185 (£250, £3,107)

Table 8 – Financial support awarded per client

Financial support awarded	Frequency	Percent
<£500	197	34.4%
£500 - <£1,000	17	3.0%
£1,000 - <£3,000	46	8.0%
£3,000 - <£5,000	150	26.2%
£5,000 - <£10,000	137	23.9%
≥£10,000	26	4.5%

The spinal unit

We did not have access to the specific data for the spinal unit. However, a report by Macmillan provides us we data and we will have accepted it as being correct. They state that, 'Working in partnership with DWP, NHS Clinicians and project staff, waiting times for benefit assessment and processing times etc. has been reduced from 30 weeks to 8 weeks. This has further reduced and decisions are now made within 9 to 10 days. This is due to a unique arrangement for this specific project with the DWP decision makers who have agreed to accept as verified the medical reports supplied by Spinal Unit Clinicians.' – for this evaluation we relied more on the qualitative data, the letters of support, and the case studies to determine the underlying theory was plausible (i.e. was it the service itself that led to the assessment and processing times, which could then contribute to fewer days spent in hospital).

Qualitative results

One of the aims of the evaluation was to explore how and why the service could result in the intended changes to patients and the NHS. The following sections outline the main ways in which the service works.

Rationale for the service

As mentioned in the background section, financial problems are a significant concern for people with long term conditions, and this interviewee sums up the situation well:

The first thing that people were most worried about was obviously, 'Am I going to get better?' so their prognosis and their diagnosis, that was the thing that people were most worried about. But the second thing that people were most worried about was financial, was about how they were going to pay their mortgage, how they were going to cope when they didn't get paid any more from work. [Interview one]

Another stakeholder also described the prominence of financial issues in a person life after they have been diagnosed:

' I would say it's right close to treatment and what my life expectancy is, is the shock of how am I going to pay my bills?' [Interview 3]

Two letters of support wrote about the changes in other services which had impacts on access to financial service,

'With the changes in Social Work Services and their location now based off site there has been an increasing difficulty accessing this service to advise the patients on the appropriate benefits to apply for and to assist them with the application forms.' (Support letter1)

Since centralisation the role of social work has changed significantly and therefore they are no longer able to offer financial or benefits advice and the route these patients are advised to take is via citizen's advice. As our patients have significantly limited mobility and are often socially isolated this is more often than not simply an option they cannot take. Therefore Sarah's input (pseudonym) has been vital in ensuring financial security is maximised. (support letter 2)

The service was set up to address these financial and service issues, particularly in those people who may be financially precarious, such that even small changes to a their financial situation could have a big impact. As mentioned in previous sections, we were not able to directly interview clients about the impact of the service on their health and wellbeing, so focus here more on the benefits to the NHS. However the graphs and figures in the previous sections strongly indicate that the service is meeting this need. The case studies also add weight to this finding.

BENEFITS TO THE NHS

The stakeholders interviewed talked about a range of benefits of the service. Several spoke of how although it was designed as a service for patients, the quick identification of need, provision of specialised advice and reduced time to successful applications also benefited the NHS. These benefits are perhaps harder to evidence and quantify, but very important. In terms of the spinal unit, one key stakeholder described the rationale behind the service and why it was felt that the service provided in the spinal unit could have a big impact:

' …it can provide a service could impact those people [in the spinal unit] really quickly and it could probably help with NHS having beds freed up as well, because hospitals and then they're waiting to get moved in there, and a lot of times we found out quite quickly as well that at the time Personal Independence Payment was taking about six months, seven months for decisions to be made on them, and we thought, well, these people's predicament, it's not going to significantly improve. …, people that have been paralysed in some form that that's the way they're going to be, and for people to get a care package which would mean adaptations and things done in their homes, that they had to be in receipt of Personal Independence Payment to have that free of charge. But people were having to wait a huge period before they could actually get an award letter through before they could get the work carried out in their house, and we saw that there was potentially a gap there. [Interview 4]

Another stakeholder further developed this idea:

'..A bed costs something like £560 a day, for them to be in there. And normally, they can't actually get out until there's a care plan put in place at their home. And in order to get their care plan they need to get their benefits maximised. And one of those benefits is personal independence payment. '[Interview 8]

One of the key benefits of having a service in the hospital is that it can identify people at an early stage that could benefit from financial advice and enable them to be discharged from hospital at an earlier stage with all the financial entitlements in place. As this stakeholder also suggested, some of the delays in processing payments were due to prosaic issues such as patients not being able to have face to face meetings about their applications:

…So in order to get that put into place [PIP], you've got to make the application. And the application is a phone call, the initial part, then you get a form out, then you're supposed to go for a face to face assessment. And, obviously, people in the spinal ward can't go for a face to face assessment. And claims were taking, roughly, maybe about 32 to 40 weeks, to get processed. [Interview 4]

One of the benefits of the service is that is it responsive and flexible. As such it can speed up administrative and bureaucratic processes significantly. Delayed discharge is a significant issue for the NHS and many of the reasons are due to not having the correct social care in place. Therefore the qualitative evidence suggests that the service may plausibly have an impact not only on the lives of the patients, but also the wider NHS. As one support letter stated:

'Working together, we have developed a health improvement initiative by improving the Personal Independence Payment process, within the Spinal Unit, in order to reduce the length of time from application to award. By adding a letter of support from the Consultant with the P.I.P application we have reduce the length of time to award to approx 8 weeks. This often means that the P.I.P award is in place in time for discharge which has a positive impact on any care package required.

The Long Term Conditions & Macmillan Financial Inclusion Services Team has proved to be an invaluable service in the Spinal Unit and loss of this service would have a detrimental long term effect on the patients here with huge implications for patients requiring care packages'.

BENEFITS TO CLINICAL STAFF

Before the introduction of the service, it was primarily up to individual NHS professionals to provide benefits advice if asked by patients. Not only did this take up their time (e.g. helping to fill in forms), many also did not feel qualified to provide the support and advice. One key stakeholder described what they thought was the potential savings to clinical staff:

…we must be saving clinical teams time about... filling in these forms but, who is that, and how would you quantify that? I suppose that is one of the other

benefits that I would see as... that the money is going back into the people's pockets and the local economy, and that hopefully we are saving time for clinical teams to allow them to focus on clinical support and clinical care, rather than dealing with fuel poverty or the risk of homelessness, or getting somebody a more suitable housing, or adaptations to their house, or actually getting a move of house if the house is unsuitable for... things that our team would intervene and actually deal with, or form filling to make sure people get what they're entitled to, or making sure their carer gets their carer's benefits, so that the carers are supported. So I suppose those would be the other things, that they would be really... they would be the other benefits of the service. [Interview 1]

Overall most of the key stakeholders (both NHS and non NHS) reported good awareness of the service. However not all NHS refer into the service, and there is still some work to be done in terms of raising the profile of the service, and its potentially unique contribution to the integrated person centred package of care. Clinicians may still be more concerned by the clinical diagnosis and treatments than the social impacts of the disease. Indeed one of the reasons for evaluating the impact of the service is to demonstrate to clinicians:

'…by showing some of the impacts ... we would actually change the mind-set of some of the clinicians to realise that somebody's social journey sometimes can be as important as their clinical journey, and if you can actually bring these two together and tie them up, and for us to work together... you [clinician] deal with the bit that you're really good at, which is the clinical journey, and help us support people. Even if it's referring to us then we can pick up the other social care issues, and the finance issues, and the things that other people are worried about' [Interview 1]

Having a 'non health' service operate within what is traditionally a clinical service sends out an important message to clinicians and other health care staff.

DID THE SERVICE ACHIEVE ITS AIMS?

One of the main aims of the welfare benefits service is to provide financial advice and support to the patient at a time they need it most (often shortly after diagnosis), and allowing them to focus on their cancer treatment and care. Another aim of the service is to reduce health inequalities by reaching those who might benefit most. Bringing together all the data suggest that the service did meet it aims. Although we were not able to interview clients, several of the key stakeholders provided us with anecdotal evidence (many used a number of case studies to demonstrate impacts) as to the potential impact:

. . I think it takes away that fear for people, if people are worried about their mortgage then we can say that, well, we'll contact the mortgage company for you and we'll say, well, this is what's happened, can you look at maybe reducing the amount that we're paying because there's mortgage holidays and things, there's all different things that we can put in place for people. [Interview 4]

The case studies and anecdotes related by the key stakeholders, combined with the quantitative data do provide plausible evidence that it achieved its aims. However, similar to many other services not all potential patients will take part or benefit. As one NHS staff member relates:

'..I mean, there are some people who just are not persuaded at all. [about being referred to the service] I do say it a few times. I'll say, are you sure? It's money you're entitled to. It's not related to what you have. I've had the odd person who just thinks it's going to be more work. I wonder if sometimes people worry that if they get additional benefits it's going to affect other benefits like their housing benefit or council tax and all these kind of things. [interview 5]

Many of the stakeholders also raised the issues of not reaching people from ethnic minority groups. This was recognised as being a 'failing' of the current service, but one which everybody was aware of and was taking steps to address.

UNMET NEEDS AND UNINTENDED CONSEQUENCES

Housing issues were viewed by many interviewees as a large unmet need and they were surprised at the prominence that housing issues would play in the lives of patients. This is perhaps unsurprising given that over 50% of clients lived in social housing. However, there was a recognition that the service needed to consider housing alongside other financial issues:

I think bringing housing to the table's been a really important aspect of it. The Wheatley housing group are the biggest registered social landlord in Glasgow, and their motto is 'better homes, better lives', and it really fits with their motto of trying to ensure that people that live in their houses have got the best quality of life as possible. So they've been a huge supporter, both financially and bringing housing expertise to the table, and I think having that 'housing dimension' to it has been one of the biggest advantages of the service, compared to any other welfare benefits service, where it's all about... primarily about financial benefits and financial gains and making sure people get the welfare benefits they're entitled to, but I think having that housing aspect has been a huge benefit; an unintended consequence really, as a result of partnership work and I don't think that can be measured. [Interview 2]

This stakeholder also raised the issue of unmet need with regard to housing and that more team members may be needed to deal with such issues:

We think that our assumption that a two day a week post supporting the housing need within the integrated team would be adequate, given the caseload and, actually, I think we will need to revise that assumption in terms of housing being a greater need, than we had envisaged [Interview 2].

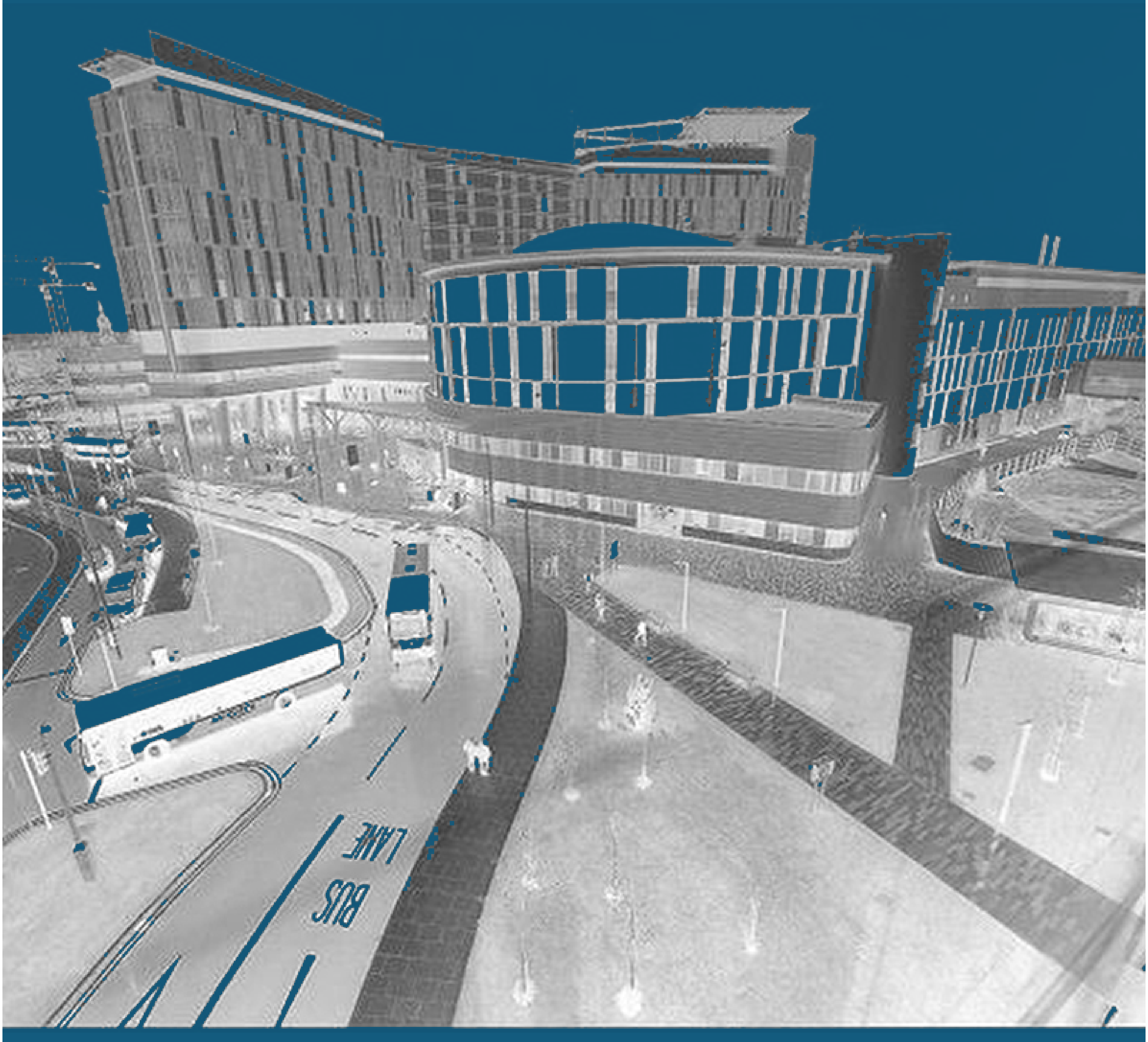
One of the support letters also mentions how the service had been the main driver for a=finding appropriate housing:

There have been several cases where Sarah (pseudonym) has been instrumental in sourcing alternative accommodation when patient's current housing was deemed unsuitable. One such case was a gentleman who was an ex-serviceman. Through Sarah's contact and knowledge of community based partnerships he was placed in a supportive programme which aimed to help people return to work and gain permanent, suitable accommodation. This would allow him to lead a more independent life after amputation.'
There was one unintended consequence that was raised during the interviews. One stakeholder said that Macmillan was often associated with cancer and how that could be confusing for patients:

'Sometimes you do get…I visit people in hospital, like today I was visiting people in hospital. The nurses have phoned in and they'll give me a name and a number and a ward and I'll go up and see people today and obviously the nurse will say, oh, Jimmy, there's somebody here to see you and if I go up and say, hello, my name's Gillian. I'm here from Macmillan I can see their faces going as if I'm there to tell them bad news. So you always have to be aware because people do associate the name Macmillan with a cancer diagnosis but quickly have to get round that and say part of my job is to come in and out of hospital and see people with long term illnesses.' [Interview 3]

Both of these issues may need to be considered in future planning of the service.

DISCUSSION & CONCLUSIONS



When evaluating this service, we were less focussed on how effective the service is in increasing financial benefits for patients (which has been answered by other studies). Rather we were interested in whether it was successful in achieving its aims and objectives, and whether it could work successfully in a NHS setting. Table 9 provides our assessment of the plausibility that the service resulted in a range of impacts.

Table 9. Linking the service to impacts

Outcome and impacts	How plausible it is that the service caused the change?	Comments
Increase in number of people receiving financial benefits	Very good	May have been due to other services or input from NHS staff but their contribution is likely to be small. Increases in people receiving some specific grants such as Macmillan grants can be almost wholly attributable to the service. Research evidence supports the link .
Decrease in time NHS staff spend on patient's financial issues	Very good	Unlikely to be due to other services or interventions
Decrease in delayed discharges	Good	Especially on the spinal unit if time to receiving PIP is significantly reduced
Decreases in anxiety and stress for patients	Moderate	Anxiety and stress can have many causes. However evidence suggests that financial issues are high on the list of worries for such patients. Research evidence is inconclusive about the link16
Better health outcomes	Unclear	Research evidence is inconclusive about the link16

Future of the service

The financial inclusion service directly impacts on the lives of people affected by cancer, or a range of long term conditions (such as those in the spinal unit). The results of the evaluation suggest that the service reaches and impacts those people who are most in need of the service. It can also be successfully implemented in a NHS setting. High quality health care is not just about the provision of traditional health services. It is also about the provision of those services which will have a long term and lasting impact on the lives of people beyond the hospital walls. Few medical interventions can claim to have such a lasting and measurable impact on the lives of people. Whilst it was not possible in this evaluation to determine the extent to which the service was more effective than having no service, it appears that it is effective in meeting its aims and objectives.

Adams J, White M, Moffatt S, Howel D, and Mackintosh J: A systematic review of the health, social and financial impacts of welfare rights advice delivered in healthcare settings. BMC Public Health 2006, 6:81.

Data collection and reporting

Overall the quality of the data is good, although the main area for improvement is increasing the uniformity with which each item is reported. Our recommendation is that the service develops a 'Standard Operating Procedure' (SOP) document that all people entering data into the database follow and if possible build rules into the database to standardise the format of each data field. For example, throughout this document we have listed the quantities of missing data, building a rule into the database to make important data fields mandatory would prevent this. Furthermore, providing staff with a standardised form to collect the data from the client should increase the completeness of the data. We recognise that these improvements are likely to be more time consuming for your staff and could be quite frustrating. However, if the data are considered important or crucial to your work we believe these improvements are necessary. See Appendix 1 for specific details.

Future research

We recommend that more research be undertaken to explore the experiences (both in the short and longer term) of people who have come into contact with the service (both patients and NHS staff). Such research could provide a more comprehensive understanding of the impact of the service.

APPENDIX 1

Recommendations for data fields to report specific issues which should be incorporated into the SOP or database rules are:

System Client ID - We have presumed that this is a unique identifier generated by the database for each new client. This number is used consistently across every case which the client has with Macmillan. **No action required**, however, having an additional identifier for each case within the client may make future analysis more efficient. We have derived this information from Case Open Date. *This System Client Case ID* only needs to be a 1 for the first case, 2 for the second etc. and could be implemented within the database; it would not need to be input by staff.

Gender – No action required. For the future and equality and diversity purposes you may want to develop a method for those recording those who are living as a different gender to the one they were born (are genetically).

Ethnicity – We could not identify whether you were using a standardised list of ethnicities such as those used by the Office for National Statistics (http://www.ons.gov.uk/ons/guide-method/measuring-equality/equality/ethnic-nat-identity-religion/ethnic-group/index.html). If a standardised list is not being used we recommend that one is implemented. Action: within the database build a drop down list derived from a standardised list of ethnicities, include these in the SOP or any standardised data collection form. Refused/declined to answer are acceptable responses in these lists.

Date of Birth – This data field follows a standard format of dd/mm/yyyy, which is good. However, there are some invalid or unrealistic dates of birth being recorded. There were four records where the *Date of Birth* and *Case Open Date* were identical. Even once these dates of birth has been set to missing there were dates of birth within 2015 and even one in 2956. **Action:** define the standard format in the SOP, data collection form and database, and set rules in the database to prevent Date of Birth which equal Case Open Date or are invalid/unrealistic.

Postcode – The format of this data field needs to be standardised, specific issues encountered included only recording the first half of the postcode, or having no or too many spaces between the two half's of the postcode. **Action:** define the standard format in the SOP and data collection form, and set rules in the database to prevent invalid entries.

Economic Status – We presume you are using a standardised list of economic statuses, if not this should be implemented. Otherwise, **no action required.**

Registered Social Landlord – **Action**: The SOP needs to specify when 'Not Applicable' and 'Not Specified' should be used.

A. Primary Diagnosis – This data field needs to be standardised. It would be useful if this could be recorded directly from a medical record such as a letter sent to the patient. There are standardised lists of medical diagnoses such as the International Classification of Disease (ICD-10, http://apps.who.int/classifications/icd10/browse/2016/en). However, these are probably too detailed for your needs. However, at present the data contains information which is not sufficiently specific such as: Visual, Tongue. When recording cancers it would be useful to record whether it is benign or malignant. Action: develop a standardised method for recording diagnosis and implement it through the SOP. It would also be useful to have a separate data field to record if the client was a Carer which then made the diagnosis data field not applicable.

Case Open Date – No action required.

Referrer Hospital – It may be worth developing a standardised list of hospital names, otherwise **no action required.**

Funding Source - It may be worth developing a standardised list of funding sources, otherwise **no action required.**

Calculated Financial Gain – We are aware of the issues you have with recording this data so our only recommendation at this stage would be to standardise the format of this data field. For example, '0.01' was considered to mean 1p, but this seems like an invalid entry, but 66000 could seem equally invalid. **Action:** use the database or SOP to standardise this field as pounds and pence.
Date of Gain – For some reason the system is recording the time alongside the date in this field. There were also 673 cases where the Date of Gain was on or before the Case Open Date, these should be considered invalid. Action: Use the database to standardise the format of this data field and rules to prevent Date of Gain on or before the Case open Date. These rules should also be explained in the SOP.

Gain Type – You could develop and standardised list of gains, but this would need regular reviewing as new types of gain became available. But being clear about whether 'Bus pass' and 'Travel pass' are the same thing would be useful. Staff would need to be able to select more than one Gain Type such as 'DLA – Mobility' and 'DLA – Care' rather than 'DLA – Both' or 'DLA, PIP or Attendance Allowance'. **Action:** consider whether this field can be standardised and if so implement through the SOP.