

# Patients' and healthcare professionals' experience with at-home parenteral therapy

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## ABSTRACT

Literature investigating the training of patients on medications self-injecting at home is lacking. This study explored patients' and healthcare professionals' (HCPs) experience with home parenteral therapy (HPT) in the UK. A clinical audit and survey of patient and HCP were conducted to inform the development of training pathway. The audit confirmed that the current training content or length are not well managed, documented or effectively communicated to the primary care providers (97.8% of discharge summaries). The cross-sectional survey was completed by 110 patients, who are on HPT and 39 HCPs involved with HPT in a UK hospital NHS Trust. HCPs and patients showed significantly different view about challenges patients faced as a result of HPT. Compared to patients, HCPs perception was that patients are mainly experiencing social implications ( $c^2 = 80.99$ ,  $df = 1$ ,  $p < 0.001$ ), followed by ability implications ( $c^2 = 55.21$ ,  $df = 1$ ,  $p < 0.001$ ), supply difficulty ( $c^2 = 24.48$ ,  $df = 1$ ,  $p < 0.001$ ) and health outcome implication ( $c^2 = 17.96$ ,  $df = 1$ ,  $p < 0.001$ ). Most patients indicated that they have not faced challenges ( $c^2 = 23.47$ ,  $df = 1$ ,  $p < 0.001$ ). The levels of training and patients support receive varied widely by condition. Patients reported inconsistency in being able to contact healthcare professional after hours when problems arise and confusion of which healthcare professional they should contact out of the treating team or the third-party supplier. There is a need to establish standardised HPT patients' training to ensure their adherence to therapy and their safety in the community setting.

**Keywords:** Home parenteral therapy, Patient adherence, Patient expectation and experience, Healthcare professionals' expectation and experience

## Introduction

The clinical homecare sector has been rapidly growing in the United Kingdom (UK) at a rate of over 20% annually. It was estimated that this could further rise to 60% if extended to all medicines that are considered to be suitable for care at home [1, 2]. In 2011 it has been reported that up to 200,000 people in England received the homecare medicines service, incurring

around UK£1 billion expenditure annually [3]. In 2019, clinical homecare accounted for up to 25% of the secondary care medicines budget and 355,000 patients were receiving clinical and medicines homecare services, accounting for UK£2.1 billion or 30% of the National Health Service (NHS) secondary care medicines budget [1]. The latest data shows that the homecare medicines services sector continues to grow in number and complexity, with over 500,000 patients and a spending of UK£3.2 billion in 2021 [4]. The National Health Services (NHS) England policy issued in 2001, entitled "The expert patient: a new approach to chronic disease management for the twenty-first century", recommends that patients should be involved in the self-management of chronic 'non-life-threatening diseases' [5]. Given the extent of the NHS expenditure and the number of patients involved, it is essential to understand and explore the patients' and healthcare professionals' (HCPs) experience, views, and perceptions of this therapy. Patient education, training, support

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and regular supervision, as well as the competency of HCPs to manage these patients, have all been identified as factors that contribute to the success or failure of self-administration of parenteral therapy at home, which might impact treatment outcomes and adherence. A literature review showed a lack of investigation into the preparation and training of patients on the use of injectable medications out of the hospital setting, its impact on their experience with therapy, and their health outcomes [6].

A study by Twiddy, [7] explored patients' experiences with Outpatient Parenteral Antimicrobial Therapy (OPAT) services in Northern England. They reported that even though OPAT provides opportunities for cost savings, the implementation is patchy and varies from one Trust to another. Another UK study, by Thorneloe [8], explored individuals' perspectives on their psoriasis, medication, and its management. It involved qualitative interviews with 20 psoriasis patients, however only one patient was self-injecting biologic therapy. Chilton and Collett [9] concluded that if a larger number of patients were to receive treatment at home, rheumatology services would need to provide more patient education and support for decision-making. A study found that 84% of patients incorrectly used their autoinjector at home, while more than half of those who made errors, missed three or more steps during the process of self-administration [10]. In addition, the forgetting curve theory suggests retention and recall of information is worsening over time without practice and repetition which could mean that 50% of the information HCPs give to their patients during the initial training about self-injecting might be forgotten within one hour, 80% might be forgotten in two days and 90% might be forgotten in a week [11].

It was therefore deemed necessary to explore the experiences of patients on other self-injectable home therapies in order to fill the gap in knowledge. This research involved conducting a clinical audit within an NHS Trust to map various processes related to Home Parenteral Therapy (HPT) and assess the current compliance with standards (phase 1). The audit was then followed by this exploration of patients' immediate-, short- and long-term experience with self-management and HPT and whether it matches the expectation of their HCPs (phase 2).

## Materials and Methods

This study was approved by the UK Health Research Authority Ethics Committee, the Life Sciences Ethics Committee at the University of Wolverhampton, and the Local NHS Trust from where patients were recruited.

### *Clinical audit*

The first clinical audit stage aimed to understand the hospital process to discharge a patient to HPT by recording the process of informing the patients and by whom, patient support during treatment, the type of injectables used at home and how many patients were on the HPT register. The second clinical audit stage aimed to understand the hospital process of discharging surgical

patients with extended pharmacological VTE prophylaxis, to assess compliance with the National Institute for Health and Care Excellence (NICE) NG89 guideline [12] and identify gaps in practice in order to suggest safety improvements in patients discharged on extended pharmacological VTE prophylaxis. All NHS Trusts follow the Healthcare Quality Improvement Partnership Ltd. (HQIP) when conducting clinical audits [13]. The clinical audit standards are:

**Stage 1:** Patients on the register are current and are still using injectables at home. Audit target: 100%.

**Stage 2:** Any person discharged with pharmacological VTE prophylaxis and their family member and/or carer (as appropriate) are either able to use it correctly or, if not, arrangements are made for someone to help them, and The GP of any person discharged with pharmacological VTE prophylaxis to be used at home is notified (source: NICE NG89 guideline (2018) recommendation: 1.2.5, 1.2.7 & 1.2.8). Audit target: 100%.

For the first stage of the clinical audit, the selection criteria were:

- Patients receiving any form of parenteral (injectable) therapy or nutrition, excluding fertility treatment, in the home setting and who continued to use injectables at home.
- Adult patient aged 18 and over.

For the second stage of the clinical audit, the inclusion criteria were:

- Adult patient aged 18 and over.
- Recently discharged from a surgical or medical ward.
- Discharged on tinzaparin low-molecular-weight heparin (LMWH) for VTE prophylaxis at home.

For the first stage of the clinical audit, the Trust's Pharmacy Homecare Medicines Service (PHMC) patient database was searched in order to identify the type of injectables used in a homecare setting, and how many patients were on the HPT register. For the second stage of the audit, a retrospective audit post discharge was carried out in adult patients discharged from the hospital wards covering a one month period, from 1<sup>st</sup> August 2020 to 1<sup>st</sup> September 2020. Patients were identified using the eScript<sup>®</sup> system, a pharmacy computer program used for clinical support and ordering medications, as well as for maintaining patient medication records and the production of electronic discharge summaries (DS). Anonymised data was collected from individual patients' electronic discharge summaries and recorded using a Microsoft<sup>®</sup> Excel<sup>™</sup> data collection sheet. A feasibility test was conducted on one patient to assess the appropriateness of the data collection tool. The audit was performed by the researcher, a pharmacist employed at the Trust.

### *Patients' and healthcare professionals' surveys*

A questionnaire-based survey of patients who were receiving any form of parenteral (injectable) therapy at home was conducted.

The study measured a number of outcomes: HCPs experiences and expectations of the patients and actual patients' experience after moving from HCPs-driven parenteral therapy in hospital to HPT, HCPs training on the delivery of HPT patient education, patients' understanding and ability to recall and apply the information and skills they were taught by HCPs when they returned home with no nursing support. Also, the duration and frequency of training provided to patients who are on long-term HPT, to re-enforce the best and safe infection control practice at home and equality of support and training for all patients on HPT regardless of the type of therapy. Approval was requested from the consultants to access their patients' records and all participants were allowed to withdraw from the study at any point.

The patients' and HCPs' questionnaires were developed by the authors (all of whom are HCPs). The questionnaire development process was conducted in accordance with the approach of Radhakrishna [14]. Appropriate changes were made to the questionnaires, based on the panel's opinion, and were pilot tested [15]. As this was an exploratory and preliminary study, the questionnaires were not fully validated, i.e. the reliability (accuracy or precision of the instrument) was not established. The patients were asked to return the signed consent form and completed questionnaire in a return-addressed prepaid envelope if they wished to participate in the study. The HCPs' questionnaire was distributed to all identified consultants who were managing patients on HPT, as well as to other HCPs at the Trust who were involved with HPT, inviting them to participate in the study. In this study, the accessible population of patients was defined as all patients who were on the Trust pharmacy homecare register/database and who were receiving any form of HPT and their consultant agreed that the patients were stable and that participation in the research would not cause them any harm. Patient sample selection was based on a non-probability sampling method that used a consecutive sampling technique (also known as total enumerative sampling), which involves enrolling every subject who meets the selection criteria during the specified time interval until a desired sample size is achieved [16]. Consecutive sampling is similar to convenience sampling, but the sampling result is more likely to represent the target population compared to the result of convenience sampling as it provides some structure and additional rigour to the resulting sample [17]. The accessible population identified from the Trust database was 640 patients who were receiving HPT and 56 HCPs. Desirable samples were calculated as 114 patients and 49 HCPs [18], however the achieved samples were 111 patients (15.9%) and 39 (69.6%) HCPs. One patient misunderstood 'parenteral' for 'parental' and her response was excluded from the study.

Statistical analysis was conducted using the Statistical Package for the Social Sciences (SPSS™, version 28) for Windows™ (SPSS™, Inc., Chicago, IL, USA), Microsoft® Excel™ (for Microsoft® 365™ MSO, version 2205) for Windows™ (Microsoft Corporation, Redmond, WA, USA) and Minitab® (version 19) for Windows™ (Minitab LLC, Chicago, IL, USA). Basic demographics were summarised using counts (frequencies) and percentages for nominal variables and means, medians, and

ranges for continuous variables. Sums of percentages less than 100% or more than 100% were the result of respondents skipping questions or selecting multiple answers, respectively. Descriptive statistics were used to calculate and present the data. Percentages, means, and frequency distribution were calculated for each of the questions. The Chi-square test of independence could not be used for the analysis of multiple response variables, as one of the assumptions of the Chi-square test of independence is that the responses are uncorrelated with each other. In order to statistically analyse multiple response questions (check all that apply format questions), which are conceptually equivalent to a series of Yes/No questions, the checked items were coded as 'Yes' (or 1) and the non-checked items as a 'No' (or 0). A Chi-square test was then performed for each response alternative separately, to find the difference between two groups of respondents.

## Results and Discussion

### 1. Clinical audit results

The first stage of the clinical audit identified 13 injectable medications used at home (adalimumab, alirocumab, brodalumab, dupilumab, etanercept, evolocumab, glatiramer acetate, golimumab, interferon beta-1a, interferon beta-1b, ixekizumab, peginterferon beta-1a, ustekinumab). The second part of the clinical audit was based on auditing the discharge of patients on extended prophylactic injectable LMWH therapy. The LMWH of choice for extended VTE prophylaxis within the Trust at the time was tinzaparin. Ninety-three patients were identified, 44 (47.3%) were male (median age; 65 years, range; 20-84 years), and 49 (52.7%) were female (median age; 59 years, range; 28-92 years). Overall median age was 62 years, range; 20-92 years. Adherence to audit standards was obtained from the audit tool. Ninety one (97.8%) of records did not show records of patient being competent in self-injecting or that arrangement was made for them to be trained. Regarding the evidence in the discharge summary that person's GP was notified that they were being discharged with VTE prophylaxis to be used at home, only 62 (66.7%) patients had records of GP notification. Twenty three (25%) had a mismatch between the electronic data entered from the prescription and the additional information written on the patient copy of the discharge summary which is not seen by the pharmacist or the GP:

1. Length of treatment not documented on DS, tinzaparin only listed as 'Drugs started in hospital' (4, 4.3%).
2. Length of treatment not documented on DS. Information given to patient: 'To continue tinzaparin while at home' (4, 4.3%).
3. Extended LMWH therapy not mentioned on DS. Length of treatment with tinzaparin documented by Pharmacy as 'GP Advice' (10, 10.8%).
4. Doctors documented 'analgesia and tinzaparin' on DS - length of treatment not documented on DS, tinzaparin only listed as 'Drugs started in hospital' (1, 1.1%).

5. Length of treatment not documented on DS, tinzaparin only listed as 'Drugs started in hospital'. Doctors documented 'No information given' as 'Information given to patient' on DS. Instructions entered on eScript in 'Patient information' to take for 28 days (this information appears on the patient's DS, not GP's); pharmacy note was for 7 days, only 7 days supplied (1, 1.1%).
6. Doctors documented 'has been educated on self-administering' on DS. However, no length of course documented on DS (1, 1.1%).
7. Extended LMWH therapy documented on DS as "Patient discharged when comfortable with...and VTE prophylaxis". Length of treatment not documented (1, 1.1%).
8. Doctors documented to take for 7 days post-discharge - Pharmacy dispensed 3 op earlier (28 days), then removed excess tinzaparin injections before discharge (1, 1.1%).

## 2. Patients and HCP surveys results

A total of 111 patients (17.3%) out of 640 returned the completed or partially completed survey, while one survey was excluded as noted above. Therefore, 110 (99.1%) of the answered questionnaires were included in the study analysis. The demographic characteristics of the study participants, grouped by medical conditions, are summarised in **Table 1**. Crohn's disease (CD) and MS were dominant diseases in females, with 17

reported cases each (23.9%), followed by high cholesterol (n=15, 21.1%), ulcerative colitis (UC, n=14, 19.7%), psoriasis (n=7, 9.9%) and atopic eczema (n=1, 1.4%). The second least reported medical condition was intestinal failure (n=3, 7.7%). CD (n=30, 27.2%) and psoriasis (n=9, 23.1%) were the most reported medical conditions among males, followed by high cholesterol (n=5, 12.8%), UC (n=5, 12.8%), intestinal failure (n=3, 7.7%). Adalimumab (Amgevita<sup>®</sup>, Humira<sup>®</sup> and Hyrimoz<sup>®</sup>) was used to treat 70% (n=21) of respondents suffering from Crohn's disease, 81.25% (n=13) respondents suffering from Psoriasis, and 88.89% (n=16) respondents reporting Ulcerative Colitis. The remaining 30% (n=9) of patients with Crohn's disease were on ustekinumab (Stelara<sup>®</sup>). Brodalumab (Kyntheum<sup>®</sup>) and ixekizumab (Taltz<sup>®</sup>), used by 6.25% (n=1) and 12.5% (n=2) patients with psoriasis respectively. Golimumab (Simponi<sup>®</sup>) was used to treat the remaining two patients (11.11%) who had Ulcerative Colitis. Patients with high cholesterol were treated with alirocumab (Praluent<sup>®</sup>) (n=9, 45%) and evolocumab (Repatha<sup>®</sup>) (n=11, 55%). Besides, dupilumab (Dupixent<sup>®</sup>) and HPN were used to treat atopic eczema and intestinal failure respectively. Patients suffering from multiple sclerosis were mainly treated with glatiramer acetate (Brabio<sup>®</sup>, Copaxone<sup>®</sup>) (n=12, 54.55%) and various types of interferon (Rebif<sup>®</sup>, Avonex<sup>®</sup> and Betaferon<sup>®</sup>) (n=6, 27.27%) and peginterferon (Plegridy<sup>®</sup>) (n=4, 18.19%).

**Table 1. Demographic characteristics of the study participants - patients (n=110)**

Characteristic	Ulcerative colitis (n=18)		Multiple sclerosis (n=22)		Atopic eczema (n=1)		Crohn's disease (n=30)		Psoriasis (n=16)		High cholesterol (n=20)		Intestinal failure (n=3)		Total (n=110)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
<b>Age Group</b>																
18 to 24 years	1	0.9%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	0.9%
25 to 34 years	3	2.7%	1	0.9%	1	0.9%	4	3.6%	2	1.8%	0	0.0%	0	0.0%	11	10.0%
35 to 44 years	5	4.5%	2	1.8%	0	0.0%	8	7.3%	2	1.8%	0	0.0%	1	0.9%	18	16.4%
45 to 54 years	4	3.6%	5	4.5%	0	0.0%	5	4.5%	3	2.7%	1	0.9%	1	0.9%	19	17.3%
55 to 64 years	4	3.6%	11	10.0%	0	0.0%	5	4.5%	5	4.5%	6	5.5%	0	0.0%	31	28.2%
65 years or over	1	0.9%	3	2.7%	0	0.0%	8	7.3%	4	3.6%	13	11.8%	1	0.9%	30	27.3%
<b>Gender</b>																
Male	4	3.6%	5	4.5%	0	0.0%	13	11.8%	9	8.2%	5	4.5%	3	2.7%	39	35.5%
Female	14	12.7%	17	15.5%	1	0.9%	17	15.5%	7	6.4%	15	13.6%	0	0.0%	71	64.5%
<b>Mobility</b>																
Dependent	4	22.2%	2	9.1%	0	0.0%	4	13.3%	2	12.5%	3	15.0%	0	0.0%	15	13.6%
Moderately dependent	0	0.0%	1	4.5%	0	0.0%	1	3.3%	0	0.0%	1	5.0%	2	66.7%	5	4.5%
Minimally dependent	0	0.0%	6	27.3%	0	0.0%	1	3.3%	1	6.3%	1	5.0%	0	0.0%	9	8.2%
Independent	14	77.8%	13	59.1%	1	100%	24	80.0%	13	81.3%	15	75.0%	1	33.3%	81	73.6%
<b>Dependence</b>																
Not responded	3	16.7%	1	4.5%	0	0.0%	1	3.3%	3	18.8%	1	5.0%	0	0.0%	9	8.2%
Dependent	3	16.7%	2	9.1%	0	0.0%	2	6.7%	2	12.5%	3	15.0%	1	33.3%	13	11.8%
Moderately dependent	0	0.0%	2	9.1%	0	0.0%	3	10.0%	0	0.0%	2	10.0%	1	33.3%	8	7.3%
Minimally dependent	0	0.0%	5	22.7%	0	0.0%	1	3.3%	0	0.0%	2	10.0%	0	0.0%	8	7.3%
Independent	12	66.7%	12	54.5%	1	100%	23	76.7%	11	68.8%	12	60.0%	1	33.3%	72	65.5%
<b>Ethnicity</b>																
White - British	18	100%	22	100%	1	100%	29	96.7%	15	93.8%	20	100%	3	100%	108	98.2%

Mixed - White and Asian	0	0.0%	0	0.0%	0	0.0%	1	3.3%	0	0.0%	0	0.0%	0	0.0%	1	0.9%
Asian British - Pakistani	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	6.3%	0	0.0%	0	0.0%	1	0.9%

A total of 39 HCPs returned the HCPs study survey, and the demographic data (age, gender and ethnicity) is shown in supplementary **Table 2**. The recruited HCPs were consultants (n=2, 5.1%), doctors (n=2, 5.1%), dietitians (n=3, 7.7%),

ward nurses (n=7, 17.9%), clinical nurse specialists (CNS, n=6, 15.4%), pharmacists (n=11, 28%) or pharmacy technicians (n=8, 20.5%).

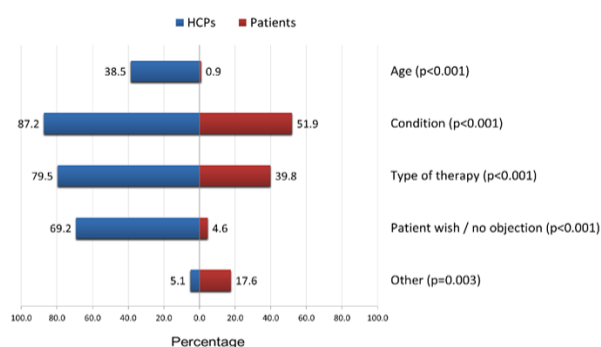
**Table 2. Demographic characteristics of the study participants – HCPs (n=39)**

Characteristic	Pharmacy Technician (n=8)		Pharmacist (n=11)		CNS (n=6)		Ward Nurse (n=7)		Dietitian (n=3)		Doctor (n=2)		Consultant (n=2)		Total (n=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
<b>Age Group</b>																
18 to 24 years	0	0.0%	0	0.0%	0	0.0%	1	2.6%	1	2.6%	0	0.0%	0	0.0%	2	5.1%
25 to 34 years	2	5.1%	5	12.8%	2	5.1%	4	10.3%	2	5.1%	2	5.1%	0	0.0%	17	43.6%
35 to 44 years	3	7.7%	3	7.7%	2	5.1%	0	0.0%	0	0.0%	0	0.0%	1	2.6%	9	23.1%
45 to 54 years	1	2.6%	3	7.7%	2	5.1%	2	5.1%	0	0.0%	0	0.0%	0	0.0%	8	20.5%
55 to 64 years	2	5.1%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	2.6%	3	7.7%
65 years or over	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
<b>Gender</b>																
Male	1	2.6%	2	5.1%	0	0.0%	0	0.0%	0	0.0%	1	2.6%	1	2.6%	5	12.8%
Female	7	17.9%	9	23.1%	6	15.4%	7	17.9%	3	7.7%	1	2.6%	1	2.6%	34	87.2%
<b>Ethnicity</b>																
White – British	8	20.5%	7	17.9%	6	15.4%	3	7.7%	3	7.7%	0	0.0%	2	5.1%	29	74.4%
White – Any other white background	0	0.0%	0	0.0%	0	0.0%	1	2.6%	0	0.0%	0	0.0%	0	0.0%	1	2.6%
Asian or Asian British – Indian	0	0.0%	2	5.1%	0	0.0%	1	2.6%	0	0.0%	0	0.0%	0	0.0%	3	7.7%
Any other Asian background	0	0.0%	0	0.0%	0	0.0%	2	5.1%	0	0.0%	0	0.0%	0	0.0%	2	5.1%
Black or Black British – African	0	0.0%	1	2.6%	0	0.0%	0	0.0%	0	0.0%	2	5.1%	0	0.0%	3	7.7%
Chinese or other ethnic group – Chinese	0	0.0%	1	2.6%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	2.6%

A combined analysis was performed to identify the differences between the two groups of participants (patients and HCPs). For categorical (nominal) survey questions, comparisons between patient and HCP participant groups were made with Pearson Chi-square statistic, using  $p < 0.05$  as a significance threshold. For the check-all-that-apply format questions, which are conceptually equivalent to a series of yes/no questions, the checked items were coded as 'yes' (or 1) and the non-checked items as a 'no' (or 0). A Chi-square test was then performed for each response alternative separately, to find the difference between two groups of respondents. All statistics were performed in SPSS®, version 28.

Overall, patients and HCPs appeared to have different perceptions of the criteria for patient eligibility for HPT (**Figure 1**). Compared to patients, HCPs were more likely to respond that age (38.5% vs. 0.9%,  $p < 0.001$ ), condition (87.2% vs. 51.9%,  $p < 0.001$ ), type of therapy (79.5% vs. 39.8%,  $p < 0.001$ ), and patient wish / no objection (69.2% vs. 4.6%,  $p < 0.001$ ) are the main criteria for patient eligibility for HPT.

**Q1. What are the criteria for patient eligibility for home parenteral therapy or nutrition?**



**Figure 1. Comparison of answers to Question 1**

While 20% of patients responded that bed availability in the hospital could be one of the reasons a person can be initiated on HPT, 56.4% of HCPs agreed to that (Q2). The remaining participants either disagreed or remained undecided (28.2 & 15.4% of HCPs vs. 31.8% & 48.2% of patients respectively,  $p < 0.001$ ). A small number of patient participants (23 out of 110, or 20.9%) and HCPs (21 out of 39, or 53.8%) shared what they believed 'long enough' for a hospital stay before starting HPT



(Figure 2a). The majority of patients indicated 1 week (30.4%) or 2 weeks (26.1%) as 'long enough', while the HCPs suggested 2 weeks (14.3%), 1 week or 3 months (9.5% each).

Only 18 out of 110 patients (16.4%), and 25 out of 39 HCPs (64.1%) answered this question about length of stay before starting HPT (Figure 2b). The majority of patients indicated 1-month (33.3%), 2-weeks (22.2%) or 1-week (16.7%) as 'too long', while the HCPs suggested 1-month (20%) or 6-months (16%) as being 'too long' for a hospital stay before starting HPT. The difference between groups was statistically significant ( $p < 0.001$ ).

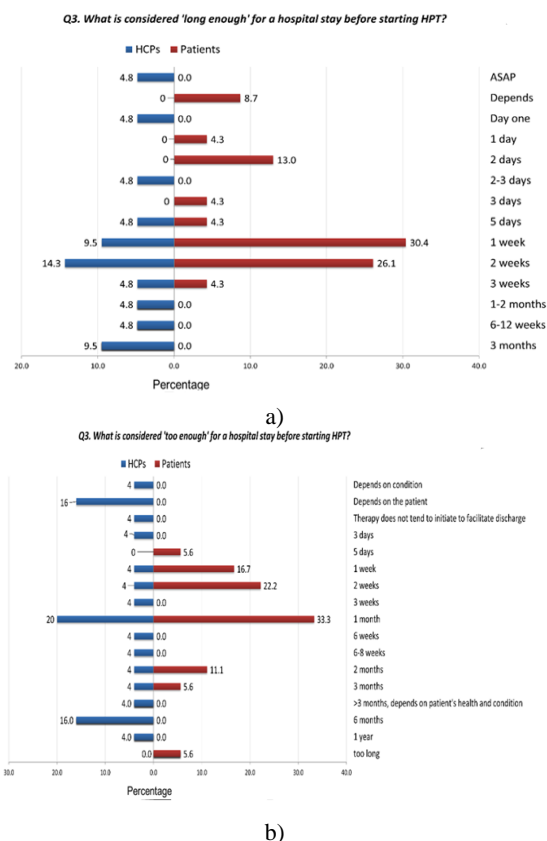


Figure 2. Comparison of answers of Question 3

Both patients (89.9%) and HCPs (100%) answered that the consultant is the main person who decides a patient's suitability for HPT. However, compared to patients, HCPs were more likely to answer that the nurse (38.9% vs. 9.2%,  $p < 0.001$ ) and the senior house officer (SHO) (8.3% vs. 0.9%,  $p = 0.024$ ) also decide about patient's suitability for HPT (Figure 3a).

The majority of HCPs (69.2%) and patients (65.5%) answered Q5; they did not know the assessment instrument used to decide a patient's suitability for HPT ( $p = 0.668$ ). A significant majority of patients responded that they did not know which guidelines were used for deciding about their HPT (Q6), compared to the HCP group of respondents (79.8% vs. 28.2%,  $p < 0.001$ ). HCPs answered that NICE guidelines (61.5% vs. 15.6%,  $p < 0.001$ ) and local trust guidelines (48.7% vs. 7.3%,  $p < 0.001$ ) were used for deciding about starting patients on HPT. For Q7, both patients and HCPs mainly suggested a 6-monthly review of patients' suitability for HPT (53.8% vs. 57.9%,  $p = 0.786$ ). However, HCPs were more likely to answer that the suitability is reviewed

during hospital admission (20.5% vs. 1.9%,  $p < 0.001$ ). Both groups mainly responded that the specialist and the nurse advise the patients about HPT at first instance. HCPs were more likely to suggest that the health practitioner (15.4% vs. 4.5%,  $p = 0.026$ ), the SHO (7.7% vs. 0%,  $p = 0.003$ ) and the pharmacist (25.6% vs. 0%,  $p < 0.001$ ) were to advise the patients about HPT (Figure 3b).

Compared to patients, HCPs were more likely to suggest that the pharmacist (41% vs. 2.8%,  $p < 0.001$ ), the ward nurses (25.6% vs. 10.2%,  $p = 0.016$ ), and the specialist (69.2% vs. 26.9%,  $p < 0.001$ ) provide education and education materials to patients starting on HPT (Figure 3c).

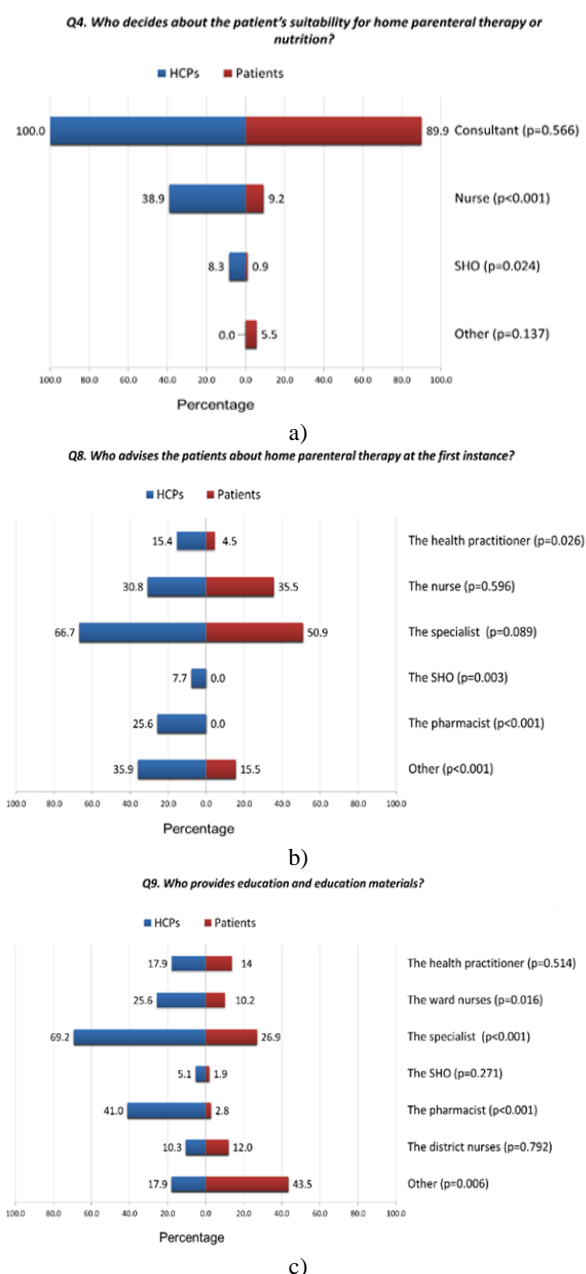


Figure 3. Comparison of answers to Questions 4, 8 and 9

While 90.9% of patients responded that they had received training in the aspects of HPT vs. only 38% of HCPs (Q10), more than two-thirds of HCPs (69.2%) vs. 9.1% of patients answered that they did not receive any training in the management of patients who are eligible for HPT ( $p < 0.001$ ).

Compared to HCPs (Q11 and 12), patients mainly responded that the training has equipped them with all they needed to know (83.6% vs. 20.5%,  $p < 0.001$ ). On the other hand, 56.4% of HCPs vs. 1.8% of patients answered that they would require additional training on HPT ( $p < 0.001$ ). The remaining agreed that self-directed learning is sufficient (17.9% vs. 11.8%,  $p = 0.335$ ).

Patients (Q12) and HCPs (Q13) were also asked if their training included information about support services navigation and availability. There was a significant difference in answering this question, where 89.9% of patients vs. 25.6% of HCP responded that the training included information about support services navigation and availability, while 74.4% of HCPs vs. 10.1% of patients responded that their training did not include this topic ( $p < 0.001$ ).

For Q13 and 14, the majority of patients (71.3% vs. 41%) responded that their training included information about infection control, while the slight majority of HCPs (59.9% vs. 28.7%) indicated that this was missing in their training ( $p < 0.001$ ).

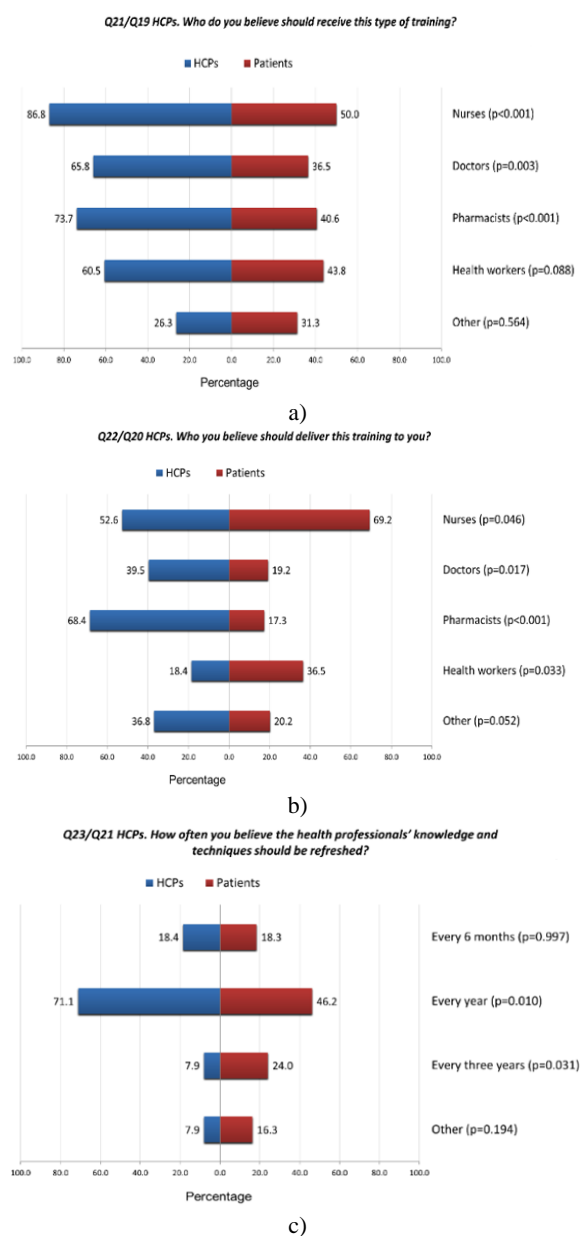
Almost all patients (95.5%) responded that their training included information about medication handling and storage (Q14) vs. only 56.4% of HCPs (Q15), while 43.6% of HCPs responded that their training did not include this information vs. 2.7% of patients ( $p < 0.001$ ).

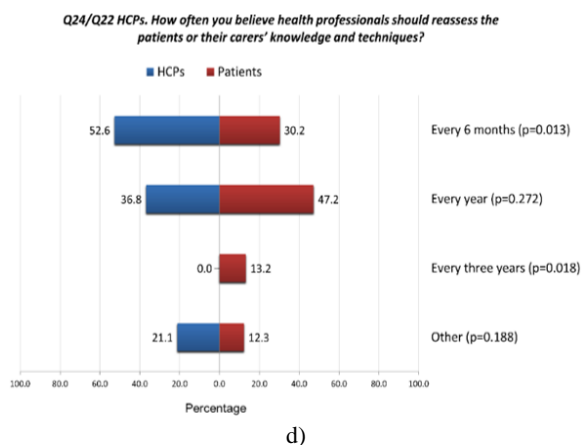
Most patients (64.6%) responded that their training included information about consumables supply (Q15), while the HCPs (Q16) mainly responded N/A (51.3%), ( $p < 0.001$ ).

Q16 and 17 on safe disposal of medical 'sharps, nearly half of HCPs (41%) selected N/A for their answer, while 15.4% HCPs responded that their training did not include information about sharps disposals, compared to 4.6% of patients. There was a significant difference in answering this question between HCPs and patients ( $p < 0.001$ ). Nearly half (47.3%) of the participants from the patients' group (Q17) responded that the training included information about biologically contaminated consumable disposal, on the other hand, 76.9% of HCPs (Q18) responded that their training did not include this information ( $p = 0.004$ ).

For Qs 18 and 19, patients 34.5%, HCPs 30.8% selected disagreed, where 23.1% of HCPs were more likely to report that their training included information about safe disposal of cytotoxic contaminated consumables, compared to patients (6.4%) ( $p = 0.018$ ). HCPs and patients had a significantly different view about what health challenges patients faced as a result of HPT (**Figure 4a**). Compared to patients, HCPs perception is that patients are mainly experiencing social implications (89.5% vs. 9%,  $p < 0.001$ ), followed by ability implication (65.8% vs. 6%,  $\chi^2 = 55.21$ ,  $df = 1$ ,  $p < 0.001$ ), supply difficulty (60.5% vs. 17%,  $p < 0.001$ ) and health outcome implication (57.9% vs. 20%,  $p < 0.001$ ). On the other hand, patients mainly indicated 'Other' health challenges (58% vs. 10.5%,  $p < 0.001$ ) where the majority (67.2% of those who responded 'Other') stated that they have not faced any challenges or health challenges. When asked about who they believe should receive this type of training (i.e. about HPT), HCPs were most

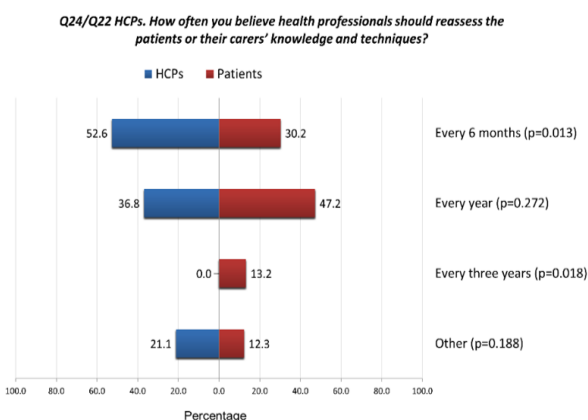
likely to suggest nurses (86.8% vs. 50%,  $p < 0.001$ ) and pharmacists (73.7% vs. 40.6%,  $p < 0.001$ ) compared to patients. Also, HCPs were more likely to indicate that doctors need this type of training (65.8% vs. 36.5%,  $p < 0.003$ ) (**Figure 4b**). When asked who they believe should deliver the HPT training to them, patients were slightly more likely to suggest nurses (69.2% vs. 52.6%,  $p = 0.046$ ) and health workers (36.5% vs. 18.4%,  $p = 0.033$ ) than HCPs, while HCPs were more likely to suggest the pharmacists (68.4% vs. 17.3%,  $p < 0.001$ ) and doctors (39.5% vs. 19.2%,  $p = 0.017$ ) should deliver the training to them (**Figure 4c**). Compared to patients, HCPs were more likely to suggest an annual review/refreshment of the HCPs' knowledge and techniques (71.1% vs. 46.2%,  $p = 0.010$ ), while patients were more likely to suggest a 3-yearly review, compared to HCPs (24% vs. 7.9%,  $p = 0.031$ ). Only approximately 18% of participants from both groups suggested a 6-monthly review (**Figure 4d**).





**Figure 4.** Comparison of answers between patients and HCPs

Compared to patients, HCPs were more likely to report a 6-monthly reassessment/review of patients' or their carers' knowledge and techniques about HPT (52.6% vs. 30.2%,  $p=0.013$ ). A yearly review was the most reported answer by patients (47.2%), but this did not statistically differ from the answers provided by HCPs (36.8%,  $p=0.272$ ). A small number of patients were also more likely to suggest a 3-yearly review, compared to HCPs who did not suggest this option at all (13.2% vs. 0%,  $p=0.018$ ) (Figure 5).



**Figure 5.** Comparison of answers to Question 24 for patients and Question 22 for HCPs

The audit showed that one-to-one consultations with the ward pharmacist, even if they happened, were not documented on the eScript® system. During the consultation, pharmacists said they would generally explain what tinzaparin is and what it is used for. They would also discuss side effects, but training on how to self-inject was mainly left for the nursing staff to deliver to the patient. Doctors neither conducted one-to-one consultations with patients about self-injecting long-term LMWH therapy nor talked to them about the risks of blood clots if the therapy was not injected as prescribed. Iverson, in the USA looked at VTE prophylaxis in pregnancy and found initially, poor compliance with training and recording but reported a quality improvement intervention improved compliance with protocols [19].

The patients' and HCPs' survey revealed some gaps that would need to be addressed with the view to improve training support to patients and HCPs and improve the effectiveness of the homecare services. According to the Professional Standards for

Homecare Services in England [20], communication and involvement of patients and carers is an important part of effective homecare services. Therefore, the criteria for the suitability of patients for HPT should be well defined, approved and shared with the patients, and they should be actively included in the decision-making process and their own assessment of suitability for HPT. HCPs should provide patients with the required information about HPT and ensure patients and/or carers are counselled, trained, and assessed as being competent to self-administer HPT. However, it is a cause of concern that the NHS HPT teams do not have access to or oversight of how their homecare patients are trained, assessed, and supported by an outsourced homecare provider. Also, while the majority of HPT patients responded that they had received training in the aspects of HPT, more than two-thirds of HCPs reported that they did not receive any training in the management of HPT patients. HCPs also answered that they would require additional training on how to provide patient education to patients starting on HPT. This is not well aligned with the expectations and requirements of the RPS standards (Standard 5 – Homecare medicines expertise) which state that all HCPs involved with HPT must be educated, trained and competent and trained in the provision of the homecare services. This lack of training might indicate that there is a lack of adequate training programme on HPT for HCPs. It could also mean that hospital HCPs involved with HPT are becoming more deskilled by outsourcing training and relying on homecare providers to deliver the training to the HPT patients. Managing home parenteral nutrition for intestinal failure is one of the more complex HPT's. Slye *et al.* looked at guidelines across the whole of Europe and found a high incidence of clearly documented standards and guidelines, but there was no audit of compliance [21].

There is a significant concern around deficiencies in training and arrangements for contaminated sharps. In the UK (and many other countries), community refuse collections have no facilities for their safe transportation and appropriate disposal. Sharps containers generally require to be returned to a medical practice or a pharmacy, where they can be directed into safe transport and disposal. Contaminated sharps finding their way into general waste collections is hazardous to staff and the community.

The second stage of the audit was focused on two standards defined by the NICE NG89 guideline (2018). As regards the first standard, the audit showed that education and training was not documented on discharge summary letters sent to the GPs. One-to-one training was conducted by nurses, not the doctor or the pharmacist, and was not recorded in the patients' main hospital record. Patient training or any arrangement for district nurse support was only recorded in nursing notes. Most, but not all, nurses would document the training. A contributing factor for failure to document training might be the lack of hospital policy on teaching patients and carers about self-administration of injectable LMWH therapy. Also, the training does not seem to be structured or standardised and might vary between nurses on how it is delivered in practice. However, this could only be an issue with the local practice because other NHS Trusts have guidance in place on how to teach patients to self-administer



LMWH injectable therapy at home [22]. Some Trusts have defined, in their clinical guidelines, that if the patient is unable to self-administer, a referral must be sent to the district nurse to continue administration at home after discharge. In this circumstance, a patient medication administration chart (PMAC) must also be filled in clearly by the prescriber before discharge and clinically checked by pharmacist [23]. In addition, clinical requirements for discharge would state that it is the responsibility of the ward prescriber and consultant to ensure the indication, dose, duration of treatment, patient's weight and renal function are all documented on the discharge letter [23]. The guideline would require the ward pharmacist, when clinically checking the discharge prescription, to ensure that the above information had been completed by the prescriber and was available on the discharge letter. The ward pharmacist would then have to complete a checklist below and endorse 'IDDA' (Indication – Dose – Duration – Administer) on the discharge prescription to indicate that the checks are complete before any supplies of LMWH are made on discharge [23]:

- Appropriate **Indication** (e.g., extended duration of LMWH)
- **Dose** – appropriate for the patient's renal function and weight and **duration**.
- Appropriately trained person to **Administer** the LMWH in the community if the patient is unable to self-administer.

The British Geriatric Society website has published informative guidelines for the administration of subcutaneous medicines by informal carers that have been developed by another NHS Trust [24]. Patients and carers involved in this procedure must undergo comprehensive training and risk assessment which is done with a help of a standard form. Checklists for informal carers administering subcutaneous medications are used to ensure appropriate patient selection and safe implementation of the policy. Medication is then prescribed onto the informal carer prescription chart by a registered prescriber.

This model of teaching and assessment, using checklists and consent forms, could be used to develop a structured, standardised, and documented training for patients and carers who would need to administer subcutaneous LMWH therapy or any other injectable therapy at home. Other studies have already shown differing levels of guidance provided by nurses on how to inject VTE prophylaxis, where some patients reported receiving training that included a demonstration and observation while others were handed the injections on discharge and instructed to complete the course of injections at home [25].

A consistent patient education programme before discharge would likely optimise adherence, effectiveness, and patient confidence with injectable therapy for the prevention of hospital associated VTE post-discharge. It was evident that treatment duration with extended LMWH post-discharge should be clearly documented in both patient's and GP's version of the discharge summary letter, although in this study, support for questions arising and who to speak to was also considered important by patients. This study also explored if the patients' and carers' experiences with HPT match the expectation of the HCPs;

broadly outcomes were positive, but there was clear room for improvement. The study also showed HPT training varies between different patient groups based on their disease, or between different HCP teams providing the training. This supports the idea of a standardised approach to training, regardless of the disease or clinical or homecare team involved, and when the HCP's have been formally trained in how to instruct, prepare and validate patients before therapy commences.

Lastly, the study aimed at exploring the patients' and HCPs' knowledge about HPT regarding the reasons why a patient is sent home on HPT, who makes this decision, how the patient is deemed suitable for HPT, which assessment instruments and guidelines are the used in this decision-making process, who provides information and education about HPT and what does the HPT training include. Again, the survey identified some significant differences in perceptions, knowledge and experiences between patients and HCPs. The results provided a better understanding of the current training and education actually given to the patients and HCPs which helped to identify areas of improvement that can facilitate a homecare service to better support patients and HCPs. The findings were also used to suggest strategies for improving homecare service in the UK. An integral part of meeting the demand and challenges for increased self-care of patients at home, in order to improve the quality of care, is a range of different integrated support and services that are required, which may include as a minimum, the inpatient or outpatient care providers, the outreach and the contracted home medication healthcare providers and primary care providers [26].

## Conclusion

The main finding was that patients' experience with HPT is not always aligned with the expectations and beliefs of HCPs. The patient education pathway (including the training material and the training process), should provide a structured, standardised, and documented training package to all patients (and/or their carers) who are discharged from the hospital to community or own home on self-injectable therapy, and should be preferably implemented at a national level. This is to decrease unwanted variation in practice, improve clinician-patient communication, and improve clinical outcomes and patient satisfaction. A consistent patient education programme before discharge could optimise adherence, effectiveness, and patient confidence with injectable therapy.

## Recommendations

- HCPs' receive training on HPT and on how to deliver training to patients who are starting self-injecting HPT. The training requires a formal, standardised and structured approach. This would improve the knowledge and confidence of HCPs and improve their ability to offer patients high-quality training and education. The lack of national guidelines suggests that patients do not receive the same training benefit and are not learning the same

information in the same manner from their HCPs. This lack of high-quality training may put patients at unnecessary stress or risk or compromise their condition clinical outcomes.

- HCPs expectations and the standards of care must be communicated to the contracted organisations that provide homecare services and a regular quality of care audit should be conducted to ensure that the contractors and their sub-contractors provide the standardised training programmes and services to patients to ensure fair and consistent services to all patients against technical agreements. The RPS Homecare Professional Standards and Audit Toolkit should be used to facilitate auditing.

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