

Report on a Survey on Holiday Dialysis Provision in Northern Ireland

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From The Executive
Committee



Northern Ireland Kidney
Patients' Association



Introduction

This report summarises the findings of a survey conducted by the Share Holiday Village in conjunction with the Northern Ireland Kidney Patients' Association and the ARK Research Centre at Queen's University Belfast. This survey was carried out as part of a feasibility programme relating to the provision of a holiday dialysis facility at the Share Holiday Village, Co. Fermanagh, Northern Ireland.

Background of the Share Holiday Village

The Share Holiday Village is situated in Lisnaskea, Co. Fermanagh. It was established in 1981 as one of Northern Ireland's projects to celebrate the International Year of the Disabled. The Centre now welcomes over 10,500 participants each year making it the largest outdoor centre in Ireland. Share works for the inclusion of disabled and non-disabled people. This is done by providing opportunities for all to participate in a wide range of creative, educational and recreational activity-based programmes. The provision of a holiday dialysis facility at the Share Holiday Village would enable a group of people with a limiting long-term illness, which creates one of the greatest degrees of dependency from high intensity medical treatment, to also benefit from the programmes on offer at the Centre.

The role of ARK in this research project

ARK, the Northern Ireland Social and Political Archive is dedicated to making social and political information available to all. ARK runs a contemporary website (www.ark.ac.uk) holding a vast amount of information on a wide range of social and political topics. ARK also provides a number of services, including technical support for people who want to carry out analyses of large-scale datasets, but do not have the resources or expertise to do this themselves.

Each year, the ARK Research Centre carries out a set amount of work for voluntary and community sector organisations that is free of charge. This will facilitate access to the most up-to-date social and political information by organisations, which are not in the position to pay for such work. The current project with the Share Holiday Village and the Northern Ireland Kidney Patients' Association has been made possible with funding from the Office of the First Minister and Deputy First Minister (OFMDFM) in Northern Ireland and with the support of the Science Shop.

1. Methodology

Three meetings took place with all involved parties prior to data collection. These meetings were set up to establish the aims and objectives of the research as well as give the researchers a better understanding of the issues that kidney patients and dialysis users face. A survey questionnaire was developed and a purposive sample was established. Arrangements were made and permission sought by Share and the Northern Ireland Kidney Patients' Association to distribute the survey questionnaires among kidney patients in hospitals. Questionnaires were completed during dialysis

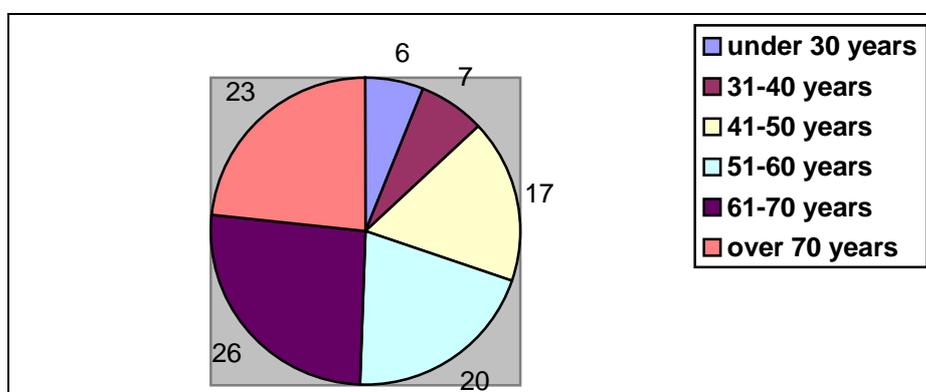
sessions and then sent back to Share. The data were input into Microsoft Excel by a Share Holiday Village volunteer and subsequently analysed by the ARK researcher using SPSS.

2. Results

Sample

In total, 153 respondents took part in the survey, 58% of the respondents were male and 42% were female. The average age of respondents was 58 years. Half of all respondents were over 60 years of age. Figure 1 shows a break down of age groups of respondents.

Figure 1: Age group of respondents (%)



Respondents who took part in the survey came from across Northern Ireland, however, over three quarters lived either in County Antrim (43.5%) or County Down (32%).

There was a wide range in the number of years that respondents had been receiving dialysis, with the average being just under four years. Over one quarter had only been dialysis users for one year or less (28.5%). Most respondents had been dialysis users for 2-5 years (45%). Seventeen percent had received dialysis for 6-10 years, and fewer than one in ten (9%) were dialysis users for more than ten years. Figure 2 shows this pattern.

No correlation or statistical difference was found between the age of respondents and the number of years they have received dialysis. Table 1 shows a breakdown of the number of years respondents had received dialysis by respondents' age group.

Figure 2: Years of dialysis received by respondents (n)

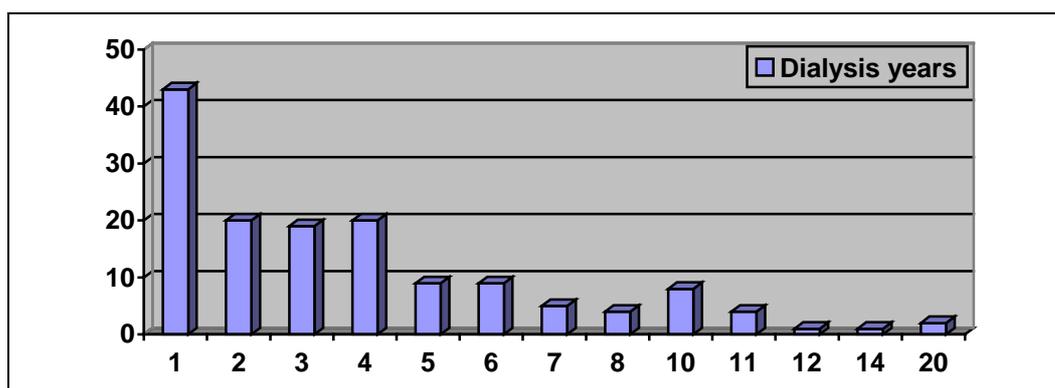


Table 1: Years of dialysis received by respondents, by age group (%)

	Age Groups					
	Up to 30	31-40	41-50	51-60	61-70	Over 70
1 year or less	11	46	16	23	36	34
2-5 years	33	46	48	47	36	51
6-10 years	44	0	24	27	13	9
Over 10 years	11	9	12	3	15	6

Ninety eight percent of respondents received haemodialysis at hospitals. 12 respondents (8%) said they were trained to do dialysis at home, but only two respondents in the whole sample said they usually received dialysis at home. This is most likely to be a direct effect of the sample selection, which was drawn from those who received dialysis in hospitals. Ninety five percent of respondents reported that, excluding travel, each dialysis session would take between three and five hours. Ninety eight percent said they had three dialysis sessions per week, with the remaining respondents saying they had four sessions.

Holiday patterns of kidney patients

From the data above it becomes clear that the vast majority of kidney patients are highly reliant on hospital facilities. Essentially, the patients' lives depend on the availability of dialysis facilities. From discussions with staff at the Belfast City Hospital Dialysis Unit and representatives of the Northern Ireland Kidney Patients' Association it has become clear during the research that hospital beds for dialysis users are in high demand. Consequently, hospitals operate a complex and rigid appointment system, and although it is possible to arrange for dialysis to take place elsewhere, the organisation of this often involves long-term planning and personal efforts.

Some respondents felt that this was a big burden. They reported feelings of dependency, exhaustion and even depression because of their medical condition. Others were more upbeat and said that receiving dialysis had actually changed their lives for the better and given them a better quality of life. Some were also said that

they did not want dialysis rule their lives. The following comments show these different approaches:

“After dialysis many patients are drained and have to have a rest. This takes part of your day out of the picture. Running up to dialysis, many patients are easily tired and often nauseous, that might restrict activities.”

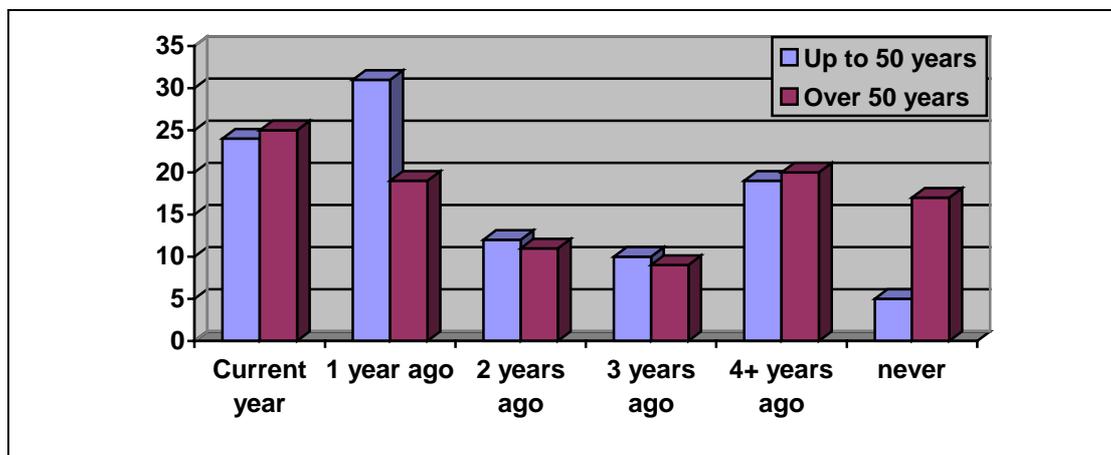
“Dialysis is very restrictive to my life in general, especially three times per week and it is only recently I have had to have dialysis.”

“Dialysis for me is a fact of life. Without it I would be fairly sick and I am thankful for the help I am getting to give me a sort of normal life.”

“Dialysis does not stop me from doing what I want to do (if possible). I do not intend to waste my time when I am at the unit. I read, watch TV, listen to music and I intend to carry on with my life.”

Sixty percent of respondents reported that they had been on holidays within the previous three years. One quarter of respondents said they had been on holidays in the current year. Thirteen percent said they had never been on holidays. Respondents who said they had never been on holidays were most likely to be over 50 years of age, as Figure 3 shows.

Figure 3: Respondents’ most recent holidays by age group (%)



More interestingly, there was a correlation between recent holidays taken and the number of years that respondents had received dialysis. Among those who had received dialysis for one year or less, 35% had been on holidays in the year before they first received dialysis treatment compared with just 20% in the current year. Among respondents who had been on dialysis for longer, a decrease in holiday activities was also found during the first two years after they had become dialysis-dependent. As Table 2 shows, half (50%) of those respondents who had received dialysis for six to ten years had taken a holiday in the year the survey was conducted compared to just one fifth (20%) of those who had received dialysis for one year or less and 23% of those who had received dialysis for two to five years.

The point in the lives of kidney patients when they become dependent on dialysis can be seen as a critical life event. This new dependency limits many patients in their everyday life activities. The survey data would suggest that patients need time to come to terms with this dependency and have to readjust their lives to the new conditions. Once this is done, most respondents seemed to be able to arrange holidays again, although others commented that they preferred not to go on holidays at all because they were most comfortable in their home hospital with familiar medical staff.

Table 2: Year of last holiday by years of dialysis received (%)

	Years of dialysis received			
	1 year or less	2-5 years	6-10 years	Over 10 years
Current year	20	23	50	7
1 year ago	35	11	14	43
2 years ago	8	17	14	0
3 years ago	5	14	0	14
4+ years	15	25	14	14
Never	18	9	9	21

The average length of the last holiday was ten days, although over 50% of these holidays had lasted between one and seven days. A very small minority of respondents (4%) reported going away for three weeks or longer. Thirty percent of respondents said their last holiday lasted for 14 days. The two most likely number of days taken were seven days or 14 days.

Over half (58%) of respondents said they had been on holiday with one other person. One third (33%) of respondents had travelled with more than one person, and less than one in ten respondents (9%) said they had been on holiday on their own. For only six percent of respondents their last holiday was an organised group event. Because of the relatively small sample size, no statistically reliable information can be extracted about the background of those eight respondents in the sample whose last holiday was an organised group event. However, a simple crosstabulation showed that there appeared to be no significant age or gender difference between those kidney patients who did go on an organised group holiday and those who did not (four were over 50 years and four were under 50 years old, three were male and five were female).

Under one third (30%) of respondents said that they did receive dialysis during their last holiday. This would suggest that the majority of respondents who were already dialysis users when they last went on holiday did either spend their holiday at home or nearby in order to be able to travel to the hospital for their treatment. Eighty percent of those who did receive dialysis when they went on holiday said it was easy to arrange. One respondent commented:

“I am fortunate enough to be fit and well enough to travel and [go on] holiday extensively while on dialysis. In the last five years the whole world has opened up to dialysis users and, providing strict control is kept re infection, it is (next to working) the most important factor in keeping mentally sane and gives us something to look forward to.”

Fifteen percent of respondents said it was difficult to make arrangements for dialysis. Again, keeping in mind that small numbers do not allow for statistically robust information, it is still interesting to note that no respondent who had organised their last holiday through a group expressed difficulties in arranging dialysis for this time.

Respondents were presented with a list of issues that may pose difficulties in arranging holidays, of which they could chose more than one. Unsurprisingly, the single most difficult issue reported by respondents was the arrangement of dialysis during holidays. Fifty four percent of respondents said they would find this difficult. Respondents commented:

“It has become increasingly more difficult to arrange haemodialysis in hospitals away from home due to the lack of slots available.”

“There are not enough places for holiday dialysis and most hospitals cannot cope with other patients wanting to go on holidays.”

“My life is built around my three nightly dialyses and this gets me down. Other dialysis patients do go to Spain and Tenerife and get dialysis there. I do not feel it worthwhile as three days of a seven day foreign holiday would be taken up at a dialysis centre.”

“Dialysis is very restricting. In the past year I’ve only visited places where there is only an overnight stay. It would be great to go away for 3-4 days and have dialysis close at hand and didn’t entail travelling too far.”

Just under one quarter (24%) of respondents felt they were financially constrained to go on holidays. This seemed to apply particularly to patients who wanted to travel to a location outside Europe and had to meet the treatment costs there themselves. One respondent said:

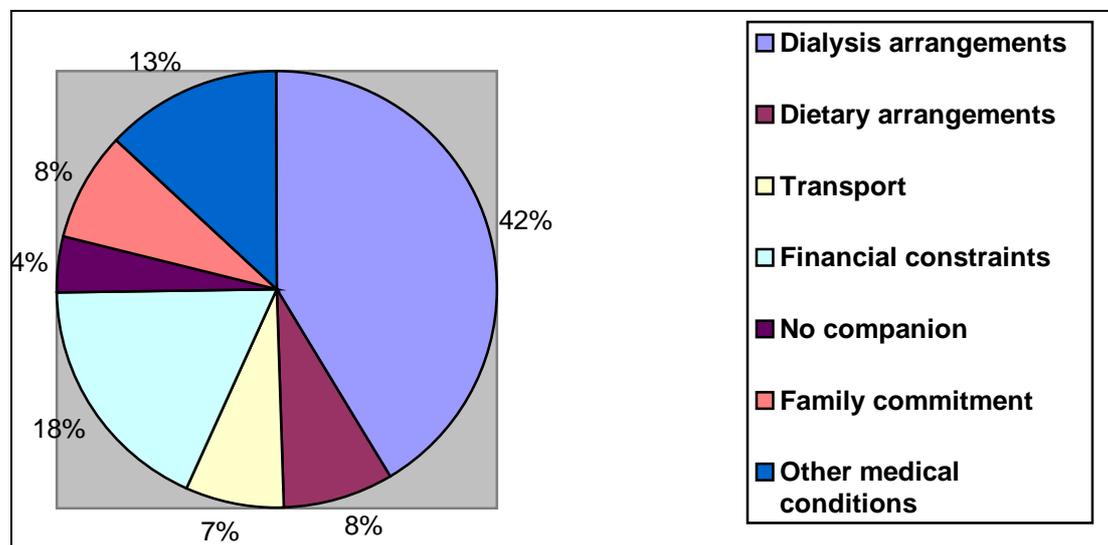
“Having been on peritoneal dialysis travelling was fairly easy. Haemodialysis so far has proved difficult because of the cost in other countries like New Zealand and the USA. I hope to go to Europe next year.”

Other medical conditions (18%) were the third most likely response by respondents when asked about difficulties that may arise in relation to holidays. Difficulties reported also related directly to the health risks involved in dialysis away from the home hospital, as the following quote shows:

“I had renal failure while away overseas, the experience was not very good, so I have not wanted to travel again. I have booked a holiday for Easter 05, that will be my first time away [for seven years].”

Figure 4 summarises all responses about the perceived difficulties in arranging holidays. About one third of respondents (31%) said they did not want to go on holidays. However, these respondents are excluded from this figure in order to ascertain what the main difficulties are for those who do want to go on holidays.

Figure 4: Reported difficulties in arranging holidays. All responses.



The figure shows clearly that the main constraint is the arrangement of dialysis during holidays (42% of all responses). 18% of all reported difficulties were of a financial kind, and 13% of responses related to other medical difficulties. A range of medical conditions was mentioned by respondents, most commonly heart conditions and diabetes.

Interest in holiday facilities for dialysis users at Share

It was the main purpose of the survey to explore the feasibility of setting up a holiday dialysis unit at the Share Holiday Village. In order to find out about kidney patients' potential interest in such a service, respondents were given a very brief introduction about the background and vision of Share. This included the information that the planned dialysis facility would not be available to local residents but exclusively to holiday makers at Share. They were also informed that the dietary needs of dialysis users would be catered for by Share. Respondents were then asked whether they would *generally* be interested in staying in a holiday village – not necessarily Share - which has dialysis facilities. Finally they were asked about their interest in a range of activities that are currently on offer in the Share Holiday Village.

Fewer than one in ten (8%) respondents had ever visited the Share Holiday Village before, which means that the majority of respondents had to express their interest based on the short paragraph they had been given in the questionnaire. Over three quarters of respondents (78%) said they would generally be interested in staying in a holiday village that provided a dialysis facility. Females (84%) were slightly more likely than males (74%) to have an interest in visiting such a holiday village and respondents under 50 years of age expressed a greater interest than those over 50 years (89% and 74%) in such a centre. Interestingly, those who said they were

interested in visiting a holiday village had received dialysis for an average of 4.3 years compared to just 2.8 years of those who said they were not interested. This may be another confirmation of the finding above that kidney patients who become dependent on dialysis are reluctant to go on holidays during the first few years after the start of their treatment. However, statistically this difference was not significant.

The following comments show the overall positive response to the idea of a holiday dialysis facility.

“I could only go on weekend breaks (locally) because of dialysis, angina and diabetes. I would like to be able to go to Share holiday village with my husband when suitable.”

“We would be very interested and would be happy to pay for it ourselves. My husband is a semi-invalid also.”

“It would be great to have a local dialysis unit at Share. If I was to take a fortnight’s holiday within Northern Ireland, one week of that would be taken up travelling back to the hospital, then staying at home overnight and travelling back again the next day.”

“I would love to have a family holiday and not to have to worry about my dialysis and diet.”

“A holiday centre in the province would be marvellous as patients could still remain ‘on call’ for transplant, being within easy reach. Since becoming ill, I have only been able to go on daytrips or overnight stays. A longer period would be something to look forward to.”

Respondents who said they had been trained to do dialysis at home, were slightly more likely to say that they would be interested in visiting a holiday village than those who were not trained for home dialysis (83% and 78%). Again, because of the numbers of those who had been trained for home dialysis were relatively small, statistically this difference cannot be regarded as reliable. Generally, in terms of the objective of the survey it is important to note that over three quarters of those who had not been trained for home dialysis said they would also be interested in a holiday village.

Sixteen percent of respondents said they would prefer to receive dialysis in a hospital and would therefore not be interested in visiting a holiday village with dialysis facilities. Some respondents said they just wanted to be at home.

Less than five percent of respondents expressed other concerns, such as not wanting to stay in a holiday village (5%) or finding it too difficult to organise transport (3%). One respondent felt that holidays in general would not be worth their while because a lot of the time would be taken up by dialysis, as the following quote exemplifies:

“With dialysis on 3 days a week, these 3 days are fully taken up with treatment, leaving just four days for other activities.”

Another respondent was afraid that a holiday village with dialysis facilities would impact on the atmosphere and the clientele at the centre:

“I would not be interested in visiting or staying at any type of holiday facility where only patients requiring dialysis or treatment are catered for. I prefer to have a holiday as far removed as possible from hospitals, dialysis and patients. The problem with staying at any holiday facility catering for patients is that all conversation etc. between holiday makers revolve around treatments and ailments.”

Some respondents stated that their interest in visiting a holiday village would depend on the fulfilment of other conditions, such as:

- the possibility that relatives could accompany kidney patients on their holidays, and
- the facilities available to relatives or partners with other long-term illnesses or disabilities.

Finally, a list of activities currently on offer at the Share Holiday Village was presented to respondents. They were asked to indicate what activities they would be interested in. Some respondents commented that because of their ill-health or age they could only enjoy a limited selection of activities. Others, however, expressed great interest in the activities on offer and felt that they needed to comment that being a dialysis user does not as such imply that activities cannot be taken advantage of:

“I have never been on a holiday where I was not involved in some serious activity. I do not like hanging about.”

Figure 5: Respondents’ interest in activities on offer at Share (%)

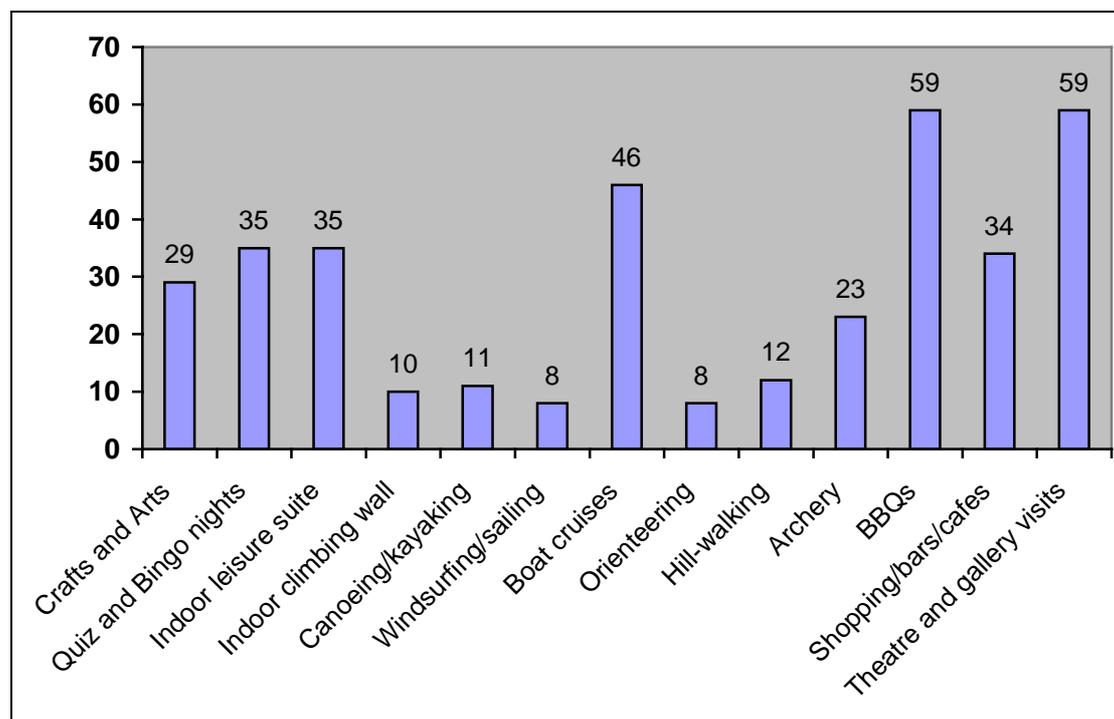


Figure 5 presents a summary of interests expressed by respondents. The figure shows that there was a wide spread of interest in various activities, although most respondents were interested in non-physical activities such as attending exhibitions or theatre performances, organising boat cruises, BBQs, visiting shops, bars or cafés nearby or having Quiz and Bingo nights. Other activities added by respondents that were not on the list in the questionnaire and were most often mentioned were fishing and sightseeing.

Conclusion

The survey showed that over three quarters of respondents were generally interested in visiting the Share Holiday Village, provided a holiday dialysis unit was available. The interest among females was somewhat greater than among males, and under 50-year olds were more likely to say that they were interested in visiting Share than older respondents. There was some interest in all activities on offer.

The data showed that more than half of respondents (54%) perceived arranging dialysis as the greatest obstacle in their holiday preparations. At the same time, the data also show that most kidney patients still go on holidays on a regular basis. The findings of the survey would suggest that the availability of a dialysis unit at Share would increase the likelihood that some kidney patients who currently seem reluctant to travel because of their dependency on hospital-based haemodialysis would consider spending time at Share. The administrative support to kidney patients in organising such a holiday seems crucial. As the following comment shows, some respondents felt that they did not have enough information available about suitable holidays.

“I think there should be more information available on holiday places where you can get dialysis and more encouragement for patients to get away to get a break from such a draining part of life. I would like weekends away, even from Friday to Monday.”

The fact that Share can equally cater for people with different disabilities and long-term illnesses as well as people without these, can certainly be regarded as an additional benefit for many kidney patients who either suffer from other long-term illnesses or who wish to travel with partners or friends who do have health problems.

Appendix 1

Survey Questionnaire



From The Executive Committee



Northern Ireland Kidney Patients' Association



Survey on Holiday Dialysis Provision

(CONFIDENTIAL)

This survey is being carried out as part of a feasibility programme relating to the provision of a holiday dialysis facility at the Share Holiday Village, Co. Fermanagh, Northern Ireland. The survey is being conducted by Share, the Kidney Patient Association and Queen's University Belfast. As a dialysis user, we are very interested in hearing your views about the proposed facility.

Any information you provide in this survey will be completely anonymous, and will not identify you in any way. Your responses will not be used for any other purpose, or passed on to any other agency. However, if you would like to receive a summary of the results of the survey, please fill in your contact details at the bottom of this page. The researchers will detach your contact details from your completed questionnaire.

Thank you for your kind cooperation in advance.

If you have any questions about the survey, please contact: Oliver Wilkinson at Share, Smith Strand, Lisnaskea, BT92 0EQ, phone 028 6772 2122, email: oliver@sharevillage.org.

✂-----

I would like to receive a summary of the results of the survey.

Name: _____

Address: _____

Postcode: _____

Email address: _____

1. What county do you live in? _____

2. Gender

(Please tick one box only)

Male	<input type="checkbox"/>	1
Female	<input type="checkbox"/>	2

3. Age in years

<input type="text"/>	<input type="text"/>
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years

Section 2: Dialysis history

4. How long have you been receiving dialysis (in years)?

<input type="text"/>	<input type="text"/>
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years

5. How many times a week do you receive dialysis?

6. What type of dialysis do you usually have?

(Please tick one box only)

Haemodialysis at hospital	<input type="checkbox"/>	1
Haemodialysis at home	<input type="checkbox"/>	2
CAPD	<input type="checkbox"/>	3
APD	<input type="checkbox"/>	4

7. On average, how many hours does each session of dialysis take (excluding travel)?

<input type="text"/>	<input type="text"/>
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hours

8. Have you been trained to do dialysis at home?

(Please tick one box only)

Yes	<input type="checkbox"/>	1
No	<input type="checkbox"/>	2

Section 3: Holidays

9. When did you last go away on holiday?

(Please tick one box only)

Never	<input type="checkbox"/>	0
This year	<input type="checkbox"/>	1
2003	<input type="checkbox"/>	2
2002	<input type="checkbox"/>	3
2001	<input type="checkbox"/>	4
Other	<input type="checkbox"/>	5

What year? _____

If you have never gone on holiday, please skip the next 5 questions and go to q15

The next few questions relate to the **last time** that you went on holiday.

10. How many days did your last holiday last?

<input type="text"/>	<input type="text"/>
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days

11. Who did you go on holiday with?

(Please tick one box only)

On my own	<input type="checkbox"/>	1
With one other person	<input type="checkbox"/>	2
With more than one person	<input type="checkbox"/>	3

12. Was this holiday part of an organised group event, for example, with the Kidney Patients Association?

(Please tick one box only)

Yes	<input type="checkbox"/>	1
No	<input type="checkbox"/>	2

13. Did you receive dialysis while you were on holiday?

(Please tick one box only)

Yes	<input type="checkbox"/>	1
No	<input type="checkbox"/>	2

If you did not receive dialysis, please skip the next question and go to q15

14. How easy or difficult was it to make arrangements for dialysis?

(Please tick one box only)

- | | | |
|----------------------------|--------------------------|---|
| Very easy | <input type="checkbox"/> | 1 |
| Quite easy | <input type="checkbox"/> | 2 |
| Neither easy nor difficult | <input type="checkbox"/> | 3 |
| Quite difficult | <input type="checkbox"/> | 4 |
| Very difficult | <input type="checkbox"/> | 5 |

15. Have any of the following issues prevented you from going on holiday in the last 5 years?

(Please tick all that apply)

- | | | |
|---|--------------------------|---|
| Difficulties or concerns about arranging dialysis away from home | <input type="checkbox"/> | 1 |
| Difficulties making necessary dietary arrangements away from home | <input type="checkbox"/> | 1 |
| Difficulties arranging transport to go away | <input type="checkbox"/> | 1 |
| Financial constraints | <input type="checkbox"/> | 1 |
| Did not have a companion to go on holidays with | <input type="checkbox"/> | 1 |
| Work commitments | <input type="checkbox"/> | 1 |
| Family commitments | <input type="checkbox"/> | 1 |
| Did not want to go on holiday | <input type="checkbox"/> | 1 |
| Other medical conditions (Please write in the box below) | <input type="checkbox"/> | 1 |

If there are any other issues that have prevented you from going on holiday in the past 5 years, please write them in the box below

Section 4: About the Share Holiday Village

The Share Holiday Village was established in 1981 and works for the inclusion of disabled and non-disabled people. Share provides opportunities for all visitors to participate in a wide range of creative, educational and recreational activity-based programmes.

Share is now considering establishing a holiday dialysis facility. This would be **available only to visitors to Share**, and would not provide services for local residents who use the dialysis unit in Omagh or Cavan. A specially trained renal nurse would be available during the dialysis session at Share, and so visitors requiring dialysis do not need to be trained in home dialysis.

Visitors can stay in self-catering accommodation, or else have their meals prepared. The Share Holiday Village would be able to meet all the dietary requirements of dialysis users. Administrative staff will be able to organise accommodation, dialysis and dietary needs.

16. Would you generally be interested in staying in a holiday village that provides a dialysis facility?

(Please tick one box only)

- | | | |
|---|--------------------------|---|
| Yes | <input type="checkbox"/> | 1 |
| No | <input type="checkbox"/> | 2 |
| It depends (please write in what it depends on) | <input type="checkbox"/> | 3 |

17. If you would not be interested, is this for any of the following reasons?

(Please tick all that apply)

- | | | |
|--|--------------------------|---|
| I do not like going on holidays | <input type="checkbox"/> | 1 |
| I would not like to stay in a holiday village | <input type="checkbox"/> | 1 |
| I would prefer to receive dialysis in a hospital | <input type="checkbox"/> | 1 |
| I find it too hard to organise transport | <input type="checkbox"/> | 1 |
| Other reason (please write in the box below) | <input type="checkbox"/> | 1 |

(Please tick one box only)

18. Have you ever visited the Share Holiday Village?

Yes	<input type="checkbox"/>	1
No	<input type="checkbox"/>	2

19. The Share Holiday Village provides a range of indoor and outdoor activities for guests. Would you be interested in taking part in any of the following if you were on holiday?

(Please tick all that apply)

Crafts and arts (painting, music, dancing, drama, pottery, video-making etc.)	<input type="checkbox"/>	1
Quiz and Bingo nights	<input type="checkbox"/>	1
Indoor leisure suite (swimming, sauna, steam room, gym)	<input type="checkbox"/>	1
Indoor climbing wall	<input type="checkbox"/>	1
Canoeing/kayaking	<input type="checkbox"/>	1
Windsurfing/sailing	<input type="checkbox"/>	1
Boat cruises	<input type="checkbox"/>	1
Orienteering	<input type="checkbox"/>	1
Hill-walking	<input type="checkbox"/>	1
Archery	<input type="checkbox"/>	1
BBQs	<input type="checkbox"/>	1
Nearby shopping, bars and cafés	<input type="checkbox"/>	1
Nearby theatre and gallery visits	<input type="checkbox"/>	1
Conference facilities	<input type="checkbox"/>	1

20. What other activities would you be interested in if you were on holiday?

21. Finally, is there anything else that you would like to add, for example, about the effect of dialysis on your life, or holiday services for dialysis users?

Thank you for taking the time to answer these questions.