

A user evaluation of the  
National Osteoporosis Society Helpline

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## 1. Executive summary

### 1.1 The evaluation

Charities Evaluation Services carried out an evaluation of the National Osteoporosis Society Helpline during 2006. The evaluation focused on what users thought of the service and outcomes for users.

Data was obtained from two main sources, interviews and postal questionnaires. Twenty phone interviews were carried out with people who had used the service. These interviews helped inform the development of short questionnaires, which were sent to 1081 phone, email and letter users of the Helpline. 695 people returned questionnaires. There was a very high response rate of 64% to the questionnaires.

### Overview of the findings

The NOS Helpline is providing an excellent service. It has a loyal customer base, which rates the service very highly. Almost all respondents said they were satisfied or very satisfied with the way their enquiry had been dealt with. Most felt the nurses were knowledgeable and gave them information that was easy to understand. For some people, NOS is providing an essential specialist service that backs up the service provided by the NHS.

The service could improve in terms of ease of getting through by phone, and the accessibility of the service to certain groups, particularly men and people from ethnic minorities. Some users wanted more information from their enquiry.

There is good evidence of significant outcomes for users in terms of improved knowledge, confidence and ability and reduced anxiety. Many have taken some positive informed action following their contact with the Helpline.

### 1.2 Findings

#### Service use

##### *Who is using the service*

- Almost all respondents were women, and white
- 83% had a diagnosis of osteoporosis; of these 47% also had fractures
- Nearly two thirds were aged 56 to 75
- Two thirds were NOS members.

##### *How they are using the service*

- Most had contacted the Helpline for themselves
- 91% had phoned, 4% emailed and 5% had written to the Helpline
- Just over half had called the Helpline more than once, 79% less than five times
- Almost half have access to the Internet.

##### *Why they are using the service*

Many had contacted the Helpline to ask for clarification of something:

- A quarter wanted clarification of something they'd heard about in the media

- Almost a third wanted help in understanding what their GP or hospital consultant had told them.

Most respondents wanted information on:

- Drug treatments for osteoporosis (59%)
- General information on osteoporosis (21%)
- Information on exercise and/or diet (20%)
- Information on pain and coping with osteoporosis (17%).

#### *Relationship of NOS to the NHS*

For most respondents, their GPs were a good source of information on osteoporosis and they reported satisfaction with that service. However, for a significant minority, this was not the case:

- One third said they felt their GP was not able to answer their questions about osteoporosis
- 13% said they did not feel able ask their GP if they had any questions
- One third felt there was not enough time within a consultation to ask questions.

#### **What users thought of the service**

Almost all respondents rated the service very highly indeed:

- Almost all were satisfied with the way their enquiry had been dealt with
- Callers felt that nurses had handled their calls well; almost all felt that the nurse had put them at ease, had listened to them and had given them enough time
- All the emailers and letter-writers felt that the nurses had answered their questions and knew the subject well
- Most email users and letter-writers said they didn't mind the wait for a reply
- All respondents said the information they had been given, either by the nurse or through written information, was easy to understand.

However, some callers are finding it hard to get through to the Helpline. A few wanted more written information, and not everyone got all the information they wanted from the enquiry.

#### **Outcomes for users**

Most respondents reported positive changes as a result of their enquiry.

#### *Improvements in knowledge*

Most respondents said that, as a result of contacting the Helpline, they:

- understood their situation better
- knew more about treatment for osteoporosis and preventing osteoporosis
- knew how to get the services they needed.

#### *Reduced anxiety*

Most people felt less worried after contacting the Helpline.

### *Increased confidence and ability to cope*

Many of the people contacting the Helpline for themselves felt more able to manage their own situation as a result of the enquiry:

- Just over half said they felt more able to make choices about their treatment
- Almost a third said they felt more able to manage their osteoporosis-related pain
- Two thirds felt more confident speaking to their doctor or other health professional about osteoporosis.

Of those enquiring about other people, most felt more able to support that person:

- Three quarters felt more able to support their family member or friend
- Most professionals felt more able to treat/support their patients/clients with osteoporosis.

### *Action taken*

Two thirds of those who had called about themselves said they had taken some action:

- 27% had met with their doctor or hospital consultant (or planned to) to discuss the information they got from the Helpline
- 17% had decided to stay on the same drug treatment
- 15% had changed their diet and/or started exercising more
- 14% had changed to a drug treatment they felt was better for them
- 10% had joined the National Osteoporosis Society.

### *Helping others*

A third of the people enquiring about family or friends said they had since helped that person deal with their osteoporosis or risk of osteoporosis. Two of the five professionals said they had improved the way they support patients/clients with osteoporosis.

## **1.3 Recommendations**

**Accessibility of the service:** NOS should consider extending their opening hours and/or providing more nurses. NOS should also consider how to attract more men and more users from ethnic minorities.

**Mode of contact:** NOS should consider the relative importance of email to their service. Only about 11% of NOS' Helpline contacts are by email, but almost 50% of the users in this survey had access to the Internet. Use of email could expand for some users and NOS might consider ways to encourage and support this.

**The role of the NHS:** NOS could consider using the findings in this survey to add weight to its campaign to get osteoporosis included in the GP contract.

**Information and support offered to users:** NOS should consider exploring further ways to increase the numbers of users getting all the information they need from their enquiry and from the written information. They should also consider whether there is anything to be done to reduce the anxiety of people who contact the service.



## **2. Introduction**

### **2.1 The Helpline**

The National Osteoporosis Society (NOS) offers support and information on osteoporosis. Its users are people with osteoporosis and their carers and families, people wishing to prevent osteoporosis and professionals working with people with osteoporosis. Support and information is primarily offered through a telephone Helpline and through local support groups.

The NOS Helpline has been running for 12 years and is based in Bath. The five staff members operate the service Monday to Friday, offering information primarily by phone, but also by email and letter.

### **2.2 The evaluation**

Charities Evaluation Services (CES) was commissioned by NOS in 2006 to undertake a user evaluation of the Helpline. The evaluation focuses on three things:

- user views of the Helpline
- service usage (how and why they are using the Helpline)
- outcomes for people using the Helpline.

The evaluation was undertaken between March and October 2006, drawing its data primarily from interviews and questionnaires. This document reports on the findings of that evaluation.

### **2.3 Summary of this report**

This report is in five sections:

Section two, *The evaluation*, describes how the evaluation was carried out and who the respondents were, and gives the reader guidance in understanding the findings.

Section three, *Use of the service*, describes how, why and how often respondents were using the service.

Section four, *What users thought of the service*, describes user satisfaction with accessibility, call delivery and content of their enquiry.

Section five, *Outcomes for users*, describes what changes there were for users as a result of their enquiry, and what action they took following it.

Section six, *Summary and recommendations*, summarises the findings and makes suggestions for future action by the Helpline.



### **3. The evaluation**

#### **3.1 Evaluation methods**

Data was obtained from two main sources, interviews and questionnaires.

##### **Interviews**

Twenty phone interviews were carried out with a group of people who had telephoned the service a month before. Respondents were chosen using a detailed sampling matrix to ensure a wide range of user types and different experiences of the Helpline were represented. Appendix one contains more details about the interview process, how these people were sampled, and the respondent characteristics. Appendix two gives the interview schedule.

The interviews were carried out before the drafting of the questionnaires, to allow the information from the interviews to shape the questionnaires.

##### **Questionnaires**

The questionnaires were 4 or 5 sides of A4, and comprised quick tick box questions with a few open questions.

##### *Who the questionnaires were sent to*

There were 2368 users of the Helpline during the period 8 May - July 14th 2006. 1081 of these gave consent to take part in the evaluation and were sent questionnaires. 695 were returned.

Overall, 45% of email and phone users gave consent to be sent a questionnaire; 22% of email users and 47% of callers. This relatively low consent rate may be due in part to the methods used; email users had to actively respond to a link in the autoreply of the nurse's email to them. Not all callers were asked during the consent period.

Letter-writers were automatically sent a questionnaire and not asked for consent. Table one overleaf gives a breakdown of consent rates.

##### *Two types of questionnaire*

There were two basic forms of the questionnaire. Both contained the same core questions, but each had some additional questions. 'Questionnaire one' was sent a week after an enquiry and focused on user satisfaction, as respondents were more likely to remember the nature of the contact soon after. As respondents needed time to take action, 'questionnaire four' was sent four weeks after the enquiry, and asked about any action taken. Each questionnaire type was tailored slightly for email, letter and phone users. Appendices 4 and 5 give the two types of questionnaire (for callers).

The questionnaires were sent to different respondent groups. A lower response rate was expected after four weeks, so about 650 questionnaire four were sent out, and about 450 questionnaire one.

Unexpectedly, the response rate for the questionnaires sent four weeks after contact with the service was very similar to those sent a week after the service; previous

evaluations found the questionnaires sent later achieved a lower response rate. Of the 695 respondents, 448 are of questionnaire four, and 247 of questionnaire one.

### *Filters*

The same form was used for people enquiring about themselves, for those enquiring about a family member/friend and for professionals. Filter questions were used to direct the different types of user to the relevant sections.

### *Piloting*

The questionnaires were piloted with almost 40 people, each being given a scenario to help them fill out the questionnaire. The scenarios included a range of user types, with different levels of satisfaction and differing experiences.

### **Response rates**

The response rate was unusually high; 64% overall. Even more unusually, 100% of letter-writers returned their forms. The high response rate may be due to the nature of the relationship with NOS, the use of a freepost envelope and/or the quality of the forms, or another unknown factor. The table below gives the consent and response rates by user type. It also gives the response rates by user type.

**Table one: respondent consent and response rates**

<b>Mode</b>	<b>Callers</b>	<b>Emailers</b>	<b>Letters</b>	<b>Totals</b>
<b>Users during evaluation period</b>	2134	199	35	2368
<b>Numbers giving consent</b>	999	47	N/a	1046
<b>% giving consent</b>	47%	24%	N/a	45%
<b>Numbers sent questionnaire</b>	999	47	35	1081
<b>Numbers returning questionnaire</b>	633	27	35	695
<b>Response rate</b>	63%	57%	100%	64%

### **The respondents**

The 695 respondents were quite similar to the user group as a whole in most characteristics<sup>1</sup>. Respondents were slightly more often white, female callers, making enquires about themselves. However, questionnaire respondents were significantly different from the main user group in that they;

- had a much higher incidence of osteoporosis and fractures
- were much more likely to be members.

Appendix three gives a detailed breakdown of respondent characteristics as compared with the NOS user group as a whole. Note that the data on respondents includes information on email and letter users, unlike the whole user group.

The reason for the differences between the respondents and NOS whole user group is unknown. However, it is possible that NOS members may be more likely to fill out a form for NOS, and those with a higher level of need regarding osteoporosis may have more interest in NOS as an organisation.

<sup>1</sup> Data from NOS Helpline annual report 2005

## 3.2 Understanding this report

### Potential sources of bias

All respondents in this evaluation, both for interviews and questionnaires, were self-selecting, both at the point of giving consent, and again on returning the form. There may be other sources of bias:

- It could be that those most satisfied are more likely to respond to a survey.
- Respondents were more likely to be NOS members.
- Respondents were more likely to have osteoporosis and fractures.
- Not all callers were asked for consent.
- For interviewees, there may be an additional bias towards people who were more available on the phone at home.
- The questionnaires excluded those who cannot read and write English.

While response rates were very high, given these potential areas of bias, caution is needed in generalising these evaluation findings to the whole user group.

### How to read the findings

#### *Who the data refers to*

All the data in the report refers to the whole group of 695 questionnaire respondents, including all user types. Where data refers to a subgroup, or the interviewees, this is stated.

#### *Who was asked each question*

Not all respondents were asked every question. There were some questions that were only asked a week after the person had contacted the service, and some only after four weeks. Also, some user types were only asked certain questions.

#### *Non-respondents*

In most questions, some respondents have chosen not to answer the question, and it cannot be known what answer these non-respondents would have given. These people have been excluded from the data. This means the percentage for each question is calculated over the total number of responses for each question, not the whole user group.

The symbol 'n' is used to denote the number of respondents to that question. To simplify reporting, and where appropriate, the value for n is given in the relevant section heading.

#### *Use of percentages*

Percentages are used for most findings. Actual respondent numbers are also given when they refer to small groups, or are needed for understanding the data. Where actual respondent numbers are very small, percentages are not used, as in these cases percentages can be misleading.

Percentages are not given for the interview respondents, as it is not appropriate to generalise from this small, purposively sampled group. The data from interviews is to add understanding and explanation.



## 4. Use of the service

### Summary of use of the service

The respondents were almost all older, white women. 83% had a diagnosis of osteoporosis; of these 47% also had fractures. Two thirds were NOS members.

Most had enquired for themselves, using the phone. 4% emailed and 5% had written to the Helpline. Almost half had access to the Internet. Just over half had called the Helpline more than once, 79% less than five times

*Many respondents had contacted the Helpline to ask for clarification of something:*

- A quarter wanted clarification of something they'd heard about in the media
- Almost a third wanted help in understanding what their GP or hospital consultant had told them.

*Most respondents wanted information on:*

- Drug treatments for osteoporosis (59%)
- General information on osteoporosis (21%)
- Information on exercise and/or diet (20%)
- Information on pain and coping with osteoporosis (17%).

Most respondents said their GPs were a good source of information for osteoporosis and they reported satisfaction with that service. However, for a significant minority, this was not the case.

The information in this section is drawn from respondents to both questionnaires.

### 4.1 Who is using the service

#### Ethnicity (n=669)

The respondents were overwhelmingly white; 99% described themselves as white or white British. Six (1%) described themselves as Asian or Asian British, and two as other or mixed. No respondents were Black or Black British, but it would be expected that fewer Black people would contact the Helpline as they are less prone to osteoporosis. Table two below compares these statistics with UK national statistics.

**Table two: comparing respondent ethnicity with UK statistics**

	<b>NOS respondents</b>	<b>UK statistics<sup>2</sup></b>
<b>White or white British</b>	99%	91%
<b>Asian or Asian British</b>	1%	5%
<b>Black or Black British</b>	0%	2%
<b>Other or mixed</b>	0%	2%

<sup>2</sup> 2001 census data national statistics online:  
<http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=10150>

These figures are consistent with NOS 2005 statistics on users, showing that 97% of their callers were white.

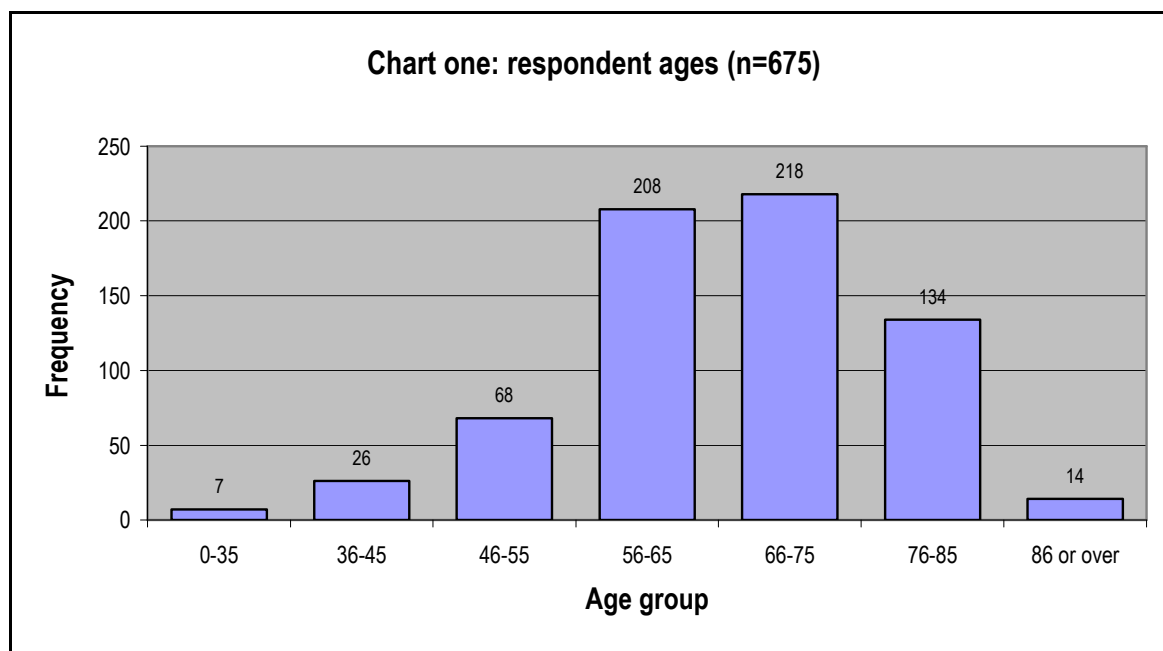
### Gender

Of the 674 who specified their gender, 35 (5%) of respondents were men. The 2005 NOS statistics<sup>3</sup> similarly found 8% of the callers were men.

Given that osteoporosis affects one in two women, and one in five men<sup>4</sup>, one would expect about 30% of users of the service (of those enquiring about themselves) to be men. This figure should perhaps even be a little higher, as amongst the respondent group men were slightly more likely than women to be enquiring about someone else. It is not known whether men use helplines generally more or less than women. Lack of recognition for the disease in men may also lead to fewer men using the service. However, the Helpline could be reaching more men.

### Age (n=675)

The majority of respondents (97%) were aged 36 to 85, with the largest numbers aged 56 to 75 (63%).



### NOS membership (n=666)

Two thirds (65%) of respondents were NOS members; this included two of the five professionals. People with osteoporosis were significantly more likely to become NOS members; 86% (365) of respondents who were NOS members also had a diagnosis of osteoporosis.

<sup>3</sup> NOS Helpline annual report 2005

<sup>4</sup> National Osteoporosis Society *Facts and Figures* booklet

## 4.2 How they are using the service

### Type of user (n=695)

The majority of respondents (91%) had contacted the Helpline for themselves. A few (7%) were enquiring on behalf of a friend or family member, and five (1%) were professionals. Men were slightly more likely to be enquiring on behalf of someone else.

Respondents had a high level of need regarding osteoporosis. The majority (83%, n=645) had a diagnosis of osteoporosis; of these, 47% also had associated fractures.

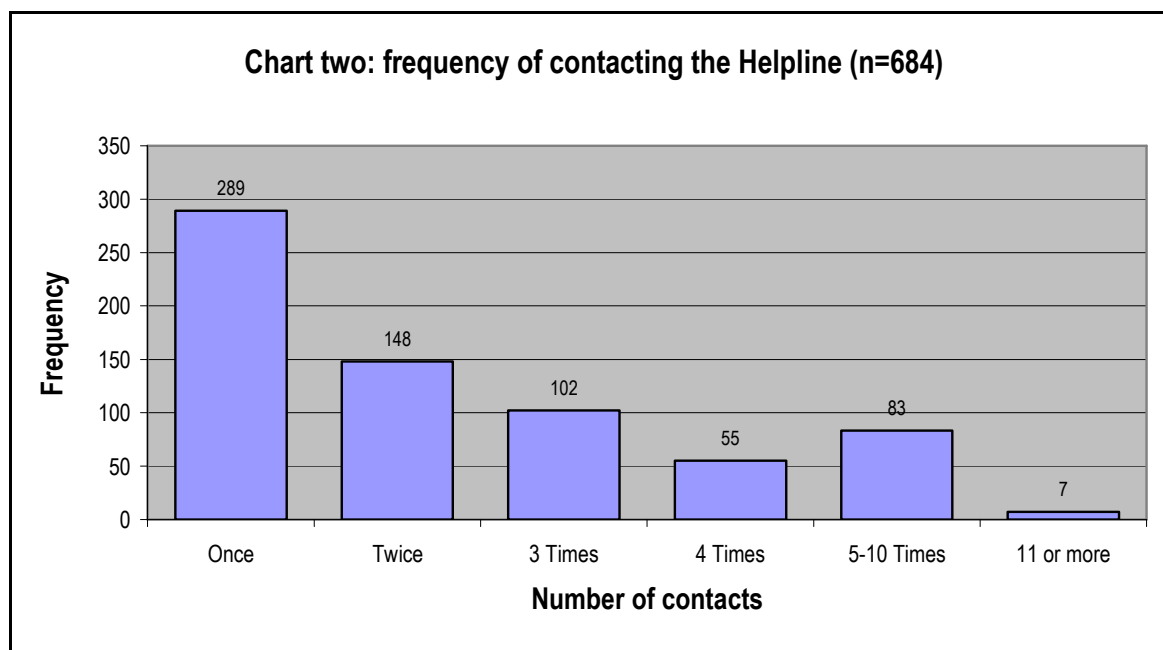
The different modes of contact have attracted slightly different groups of people:

- Email users tended to be younger than callers or letter-writers and were less likely to have a diagnosis of osteoporosis and associated fractures.
- Letter-writers tended to be older than callers or emailers and were more likely to have a diagnosis of osteoporosis and have associated fractures.

### Frequency of contact (n=684)

Just over half of the respondents (58%) had contacted the Helpline more than once. The majority of respondents (79%) reported having contacted the Helpline less than five times; 45% had done so two to four times. These overall figures disguise the following differences:

- Callers had contacted the Helpline more often than email or letter-writers.
- Female respondents had contacted the Helpline more often than men. 60% of men had called just once, compared with 40% of women.
- Respondents who are members of NOS made enquiries much more often than non-members. For example, of the 87 people who said they had contacted the Helpline more than five times in the past, 89% (78) were NOS members.



There was no correlation between how satisfied a user was and how often they contacted the Helpline.

#### *Discussion – men and the Helpline*

Men are less likely to be repeat callers than women. That NOS collect demographic data on all callers, without screening out repeat users, may inflate the numbers of women using the Helpline.

It may be significant that men make enquires less often than women. The reasons for this are unknown, but possibilities include the following:

- They may get all they need within one enquiry and not need to contact the Helpline again.
- Something about the nature of the contact may make them less keen to enquire again.
- They may be disproportionately put off by the difficulties getting through.

#### **Access to the Internet (n=666)**

43% (284) of those who contacted the Helpline by letter or phone said they had access to the Internet. To this figure should be added the 27 email users; this means that 45% of the respondents (n=693) had access to the Internet.

Callers were over twice as likely to have Internet access than letter-writers; only six letter-writers had access to the Internet.

#### **Written material (n=656)**

Most respondents (68%) said they had been sent written material. All respondents said they had read the material, regardless of time elapsed since the contact with NOS.

Letter-writers were most likely to be sent written material, and email users most unlikely. This presumably reflects the ease of sending additional materials to letter-writers.

### **4.3 Why they are using the service**

#### **Clarifying information from a third party (n=695)**

Many respondents had contacted the Helpline to ask for clarification of information they had from a third party; in effect, they wanted a second opinion from NOS. 26% wanted clarification of explanation of something they'd read or heard about in the media. One explained that 'I have been on Fosamax for 10 years. I am concerned about coming off it because of a media report of worse degeneration'.

Almost a third (28%) wanted clarification of something they had heard from their doctor or consultant:

- Almost a fifth (19%) wanted help in understanding what their GP had told them
- 14% wanted help in understanding what their hospital consultant had told them.

### What information was wanted (n=695)

The majority of users (59%) wanted information on drug treatments for osteoporosis. The other most common reasons for enquires were:

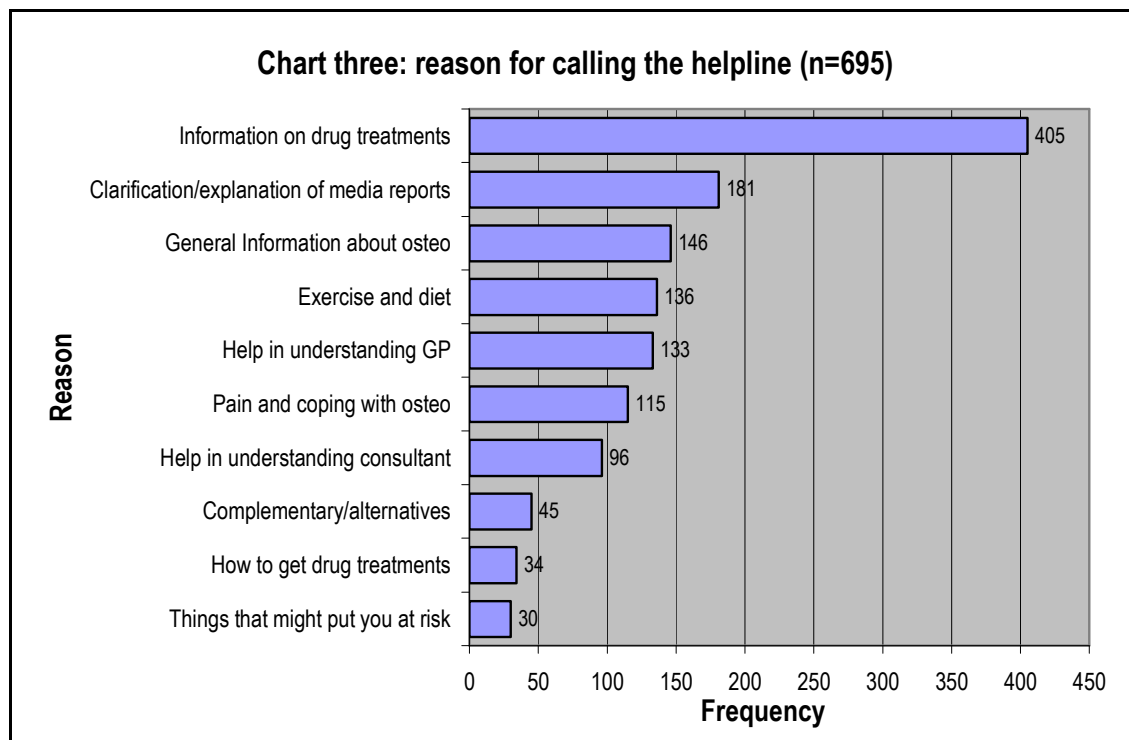
- general information on osteoporosis (21%)
- information on exercise and/or diet (20%)
- information on pain and coping with osteoporosis (17%).

More specialised enquiries included:

- Complementary/alternative therapies (6%)
- How to get drug treatments or tests, including bone density scans (5%)
- Things that might put one at risk of osteoporosis (4%)
- National Osteoporosis Society support groups (4%)
- Other medical issues and their relation to osteoporosis, for example a skin rash (2%, 16)
- Financial help/State benefits (1%, 4).

Two of the professionals mentioned additional specific reasons for their enquiry:

- Clarification of information on the website for use in school and at health days for a support group.
- General advice on developing a risk assessment for osteoporosis.



#### **4.4 Relationship of NOS to the NHS**

All respondents who had called about their own situation were asked about the role of their GP. For most of these, GPs were a good source of information for osteoporosis and they reported satisfaction with that service. However, for a significant minority, this was not the case.

##### **Knowledge of osteoporosis**

The majority of respondents (63%, n=496) said they felt their GP was able to answer their questions about osteoporosis. However, 27% said they felt their GP was not able to answer such questions. This last response was echoed by six of the interview respondents. One explained that, although their doctor had been very good, they 'only knew about one tablet'.

Some respondents in the interviews expressed frustration with the situation. One explained that 'you don't realise until you're in the position [yourself] how difficult it is to obtain the information by conventional routes'.

##### *Patients informing doctors*

Two questionnaire respondents and two interviewees mentioned that they felt they were informing their doctors about osteoporosis. One explained that:

*Having had the results of my scan explained by the Helpline, I was then able to tell my GP what the results meant! I also gave my practice nurse a copy of the diet sheet I obtained from NOS.*

For some of these respondents, their doctors have welcomed the information from NOS. One explained that NOS information had weight with their doctor and consultants, whereas if they presented them with information from the Internet the doctors were more sceptical. However, one questionnaire respondent reported that their consultant felt NOS information was inaccurate.

##### *Trust*

For five of the interview respondents, there was an issue of trust; they didn't trust the NHS as much as NOS. For example, one explained that they felt NOS had no budgetary constraints when giving information about drugs. Three people explicitly said that they had called NOS for a 'second opinion'.

##### *Contradictory information*

Three questionnaire respondents and one interviewee mentioned that it was sometimes problematic that NOS gave different information to their doctors.

##### **Feeling able to ask questions**

Most people (83%, n=543) felt able ask their GP if they had any questions. However, 13% said they did not feel able to ask questions of their GP. One interviewee felt that being able to ask questions was vital; 'you hear such horror stories of people who don't ask questions'.

Feeling unable to ask questions may be due, in part, to lack of consultation time. Although most felt that there was enough time within a consultation to ask questions, this percentage was smaller (64%, n=510). And for 31% of respondents there was not

enough time during a visit to the doctor to ask all the questions they wanted to. A few interview respondents explained that they did not want to trouble their doctor.

Two interviewees said that the fact they could call NOS whenever they needed information, and get 'instant contact' as opposed to having to wait for an appointment, was helpful. Three interviewees commented that they felt the NHS was not interested in prevention.

#### *Using NOS as a preparation*

Two questionnaire respondents and three interviewees commented that they called NOS before seeing their doctors, to enable them to be more informed, and to help them to 'ask more searching questions'. One interviewee explained that this was a practical response to short consultation times, so they could 'go armed, knowing what you want to get out of the appointment time'.

### **Discussion**

A large number of respondents in this survey felt their GP was not able to give them the information they needed. It is possible that NOS users represent a disproportionate number of people unable to get the information they need from their GP, and that this is also reflected in the questionnaire responses.

These findings may reflect an acceptable lack of specialism in GP practice; it may also relate to the absence of osteoporosis in the GP contract.



## 5. What users thought of the service

### Summary of what users thought of the service

*Almost all respondents rated the service very highly indeed:*

- Almost all said they were satisfied or very satisfied with the way their enquiry had been dealt with
- Callers felt that nurses had handled their calls well; almost all felt that the nurse had put them at ease, had listened to them and had given them enough time
- All the emailers and letter-writers felt that the nurses had answered their questions and knew the subject well
- All respondents said the information they had been given by the nurse, or through written information, was easy to understand.

*However,*

- Some callers are finding it hard to get through to the Helpline
- A few wanted more written information
- Not everyone got all the information they wanted from the enquiry.

All respondents were asked about what they thought of the service. Those filling out a form a week after their contact with the service (231 people) were also asked more detailed questions. This section contains data from both the whole group and this subgroup.

### 5.1 Accessibility of the service

#### Ease of getting through by phone

Some callers are finding it hard to get through to the Helpline. Although 90% of callers (n=222) said they found it easy to get through, 9% (18 people) said they did not find it easy. However, this figure was higher amongst those suggesting improvements.

Of the 67 people suggesting improvements, the majority (44) had comments about the accessibility of the service in terms of opening hours and ability to get through. Thirty-one people said that it had been hard to get through to the service; several said they 'almost gave up trying', although some added that it was 'worth persevering' and had much praise for the Helpline. One had written after having no success on the phone. One specified that Mondays in particular were difficult.

NOS staff recently carried out a separate monitoring exercise, asking all callers about how often they had called to get through; 50% said they had no problem getting through, 25% tried twice and 25% tried several or many times. This can be compared to the findings of a recent benchmarking report written for NOS<sup>5</sup>, which found that 50% of calls to the Helpline are not answered.

Various suggestions were made for improving the accessibility of the service, including:

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<sup>5</sup> Catherine Brown (2006), *Helpline Services Benchmarking: Final Report*, NOS

- Extended opening hours (10)
- More staff (6)
- Opening evenings and weekends (2).

In terms of call management, a few additional comments were made:

- Two respondents didn't like the 'mechanical voice' that told them the lines were busy
- Two would have preferred to hear an engaged tone rather than a recorded announcement
- One would have liked to leave a message for a call back.

### **Length of time for email or letter replies**

NOS staff have a target of replying to emails within five working days, and letters within ten. Of the 11 letter-writers who responded to this question, ten said they didn't mind waiting that long. One felt the waiting time was too long. Of the 26 emailers who responded to this question, 21 said they didn't mind the wait, one felt it was too long, and four said they could wait longer.

NOS Helpline staff have expressed concern about the time required to reply to letters and emails. There may be good practice reasons for reducing the waiting time. However, whilst the numbers here are too small to make definitive generalised statements, this data suggests that these respondents were not too concerned about the wait.

## **5.2 Service delivery**

### **Overall satisfaction with the enquiry (n=671)**

Respondents rated the service very highly indeed. Many described the Helpline using words like 'excellent' and 'helpful'. One explained that:

*The service provided by NOS is FAR FAR superior than any of the other various organisations I have had dealings with. You are treated as a responsible intelligent adult. Would that it were so easy everywhere. Have been member for 10 years, and all your information is most welcome. (Respondent's emphasis.)*

Almost all (98%, n=671) respondents said they were satisfied or very satisfied with the way their enquiry had been dealt with; 80% were very satisfied. One explained:

*I found the nurse who answered my questions very professional and helpful - she answered clearly and in terms I could understand. She was very sympathetic and really put my mind at rest. My phone call was superb and I really can't say anything can be improved in the service. Thank you for being there at the end of a phone call.*

Thirteen (2%) said the way their enquiry had been dealt with was adequate, and two said they were not very satisfied. No reasons were given for their dissatisfaction. One did say that the written information they were sent was not enough, and that overall they needed a lot more information from the enquiry. The other reported being more anxious after the call, which may explain their dissatisfaction.

One interview respondent, who had called the Helpline 5-10 times over a long period of time, said that once they had spoken to a nurse who was not very helpful, but had since found the service excellent.

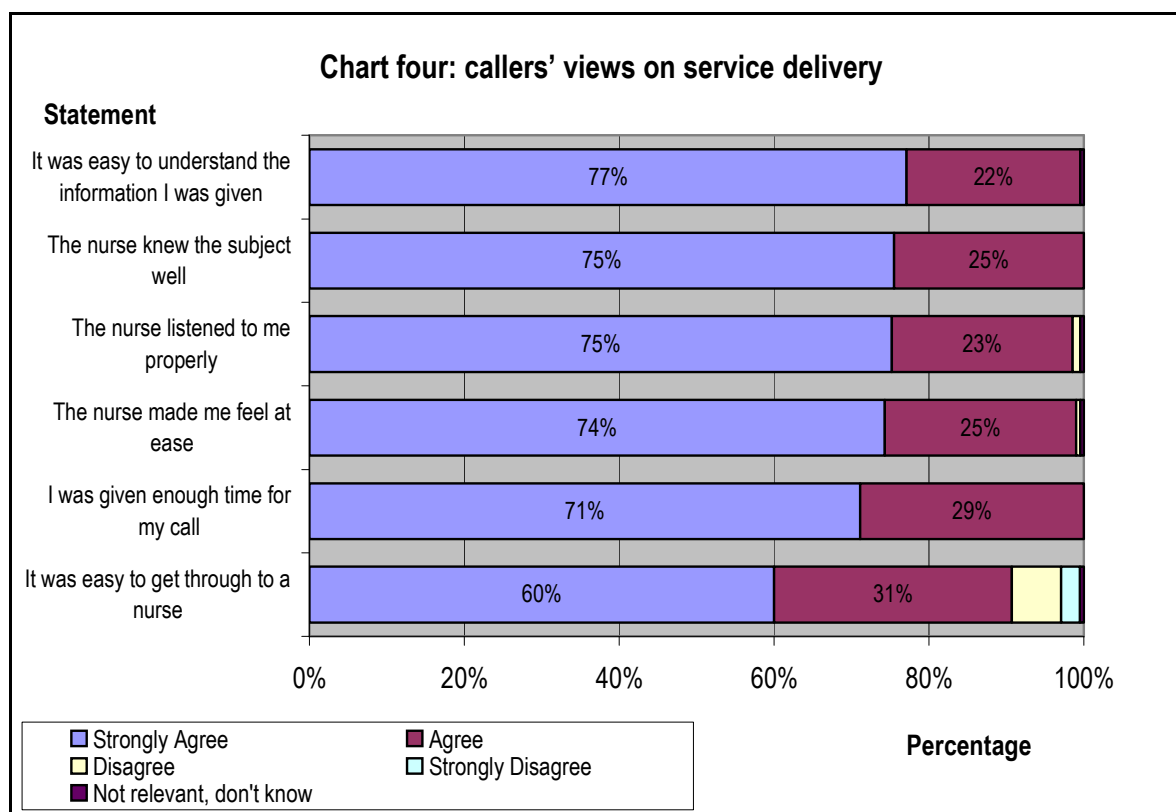
There were some differences in terms of satisfaction and caller type. Letter-writers felt less satisfied with the way their enquiry had been dealt with than callers and emailers. For example, 81% callers said they were very satisfied with the way their enquiry had been dealt with, whereas only 63% (20) of letter-writers said this. The reasons for this are not known.

### Call delivery

Questionnaire one respondents who had phoned the Helpline were asked more detailed questions about how their call was handled.

Callers felt that nurses had handled their calls well; almost all (98%, n=216) felt that the nurse had put them at ease, and a similar number (99%, n=219) felt the nurse had listened to them. Two people felt the nurse had not listened to them well.

Almost all (99%, n=213) said they felt the nurse had given them enough time. However, one respondent did later say they had felt a little rushed. When asked if the service could be improved, one respondent said that this was 'Impossible. It's a hugely reassuring Helpline. The nurses so helpful, no condescension and help with the simplest and most obvious question easily. Thank you.'



## **Getting through to a specialist**

Four interviewees specifically commented that they appreciated getting through to an expert immediately; 'someone who knew what you were talking about – not passed from pillar to post...that impressed me'.

### **5.3 Satisfaction with content**

All callers responding to the question said the information they had been given was easy to understand. Almost all (98%, n=229) felt that the nurse who took their call knew the subject well. One explained that they were:

*Very satisfied. It is reassuring to speak with sensitive authoritative personnel. I would be happy to phone again in the knowledge that my questions would be answered.*

For some, NOS was the only source of information for them. An email respondent explained that:

*The questions I asked were ones from which I had requested information from many professionals; physios, GP's, yoga teachers and none of these people were able to answer. Thanks NOS.*

All the emailers (10) and letter-writers (6) responding to questionnaire one felt that the nurses:

- had answered their questions,
- knew the subject well, and
- gave information that was easy to understand.

However, one respondent felt that the nurse did not know the subject well. Another felt that 'whilst I understand the nurse can't know every illness my other medical conditions were not taken into account when she gave me her answer.'

### **Judging accuracy**

It is not easy for users of the Helpline to judge its accuracy. However, there was a strong feeling from interview respondents that they trusted NOS and felt the information given was accurate; one explained that 'as far as osteoporosis is concerned, I'd check anything with them'. One reported that in their experience, if NOS didn't know the answer they would call them back later with the answer.

### **Written material**

Almost all of those who had been sent written material (96%, n=441) said it was the right amount of information. Three (1%) said it was too much, and 12 (3%) said it was not enough. One of the latter explained that the leaflet she received was 'only an outline/brief summary. I would like to know more about the subject.'

All respondents (n=450) said the information they had been sent was easy to understand.

### **Whether they got the information they wanted**

Most respondents (65%, n=653) said they got all the information they needed. However, a significant number did not get all the information they wanted:

- 27% (174) got most of what they needed
- 5% (35) got some of what they needed
- 16 needed a bit more
- 2 needed a lot more.

Of the two who needed a lot more, no explanations were given as to what would have been helpful. One of these people also said they were dissatisfied with the way their enquiry was dealt with; the other said they were satisfied. Both these people felt the written material they had been sent was not enough.

No differences were found regarding whether or not people got the information they wanted and whether they had been sent written information; those who were sent written information were no more or less likely to say they wanted more information.

Letter-writers were less likely to say they had got everything they wanted from the call. A similar number of emailers (68%) and callers (66%) said they had got everything they needed. Only 48% (12) of letter-writers said this. This figure is based on small numbers and may therefore just be due to chance.

It is worth noting that although letter-writers wanted more information than callers or emailers, letter-writers were more likely to be sent additional written information. It may be that the content of the letter reply to them lacked what they needed.

It may be that NOS would not have been able to provide all these users with all the information they wanted. However, it does seem that some could have been provided with more.

### **Consistency of NOS messages**

Two respondents felt that the Helpline needed to be more consistent in its messages. One explained that 'When I spoke to two different nurses at two different times I received contrary information. This should be avoided if possible as it is very confusing.' The other reported that:

*The fact file "Healthy New Bone" suggested long-term use of Fosamax "might eventually have adverse effects on bone strength and fracture risk." The nurse had not heard this might be the case, although it has since been reprinted in "Osteoporosis News", the NOS magazine. Perhaps the nurses themselves need to be informed of concerns at an earlier stage.*

Another respondent made a request that osteoporosis not be referred to as a disease, explaining that 'it makes me feel contaminated. Condition is an easier term to deal with for me.' This respondent said that the Helpline staff never use the term disease, and that it only occurs in the information packs.

#### **5.4 Recommendations for improvements beyond the Helpline**

Most recommendations from respondents have been integrated into the report findings. However, several respondents made recommendations beyond the remit of the Helpline.

Four people suggested improvements to do with other people:

- Two wanted to be able to get in touch with other people with osteoporosis - it is not known whether a local support group would have been an appropriate option for these people.
- Two wanted to know more about how other people had experienced particular drugs and their side effects.

A few suggestions were made for the NOS magazine:

- More on research (2)
- Less on local groups
- More on men, 'and not just at the back of the mag!'

## 6. Outcomes for users

### Summary of outcomes for users

Most respondents said that, as a result of contacting the Helpline:

- they understood their situation better and knew more about osteoporosis
- they felt less worried.

Many of the people contacting the Helpline for themselves felt more able to manage their own situation as a result of the enquiry:

- Just over half said they felt more able to make treatment choices
- Almost a third said they felt more able to manage pain
- Two thirds felt more confident speaking to their doctor or other health professional about osteoporosis.

Two thirds of those who had called about themselves said they had taken some action:

- A third had met with their doctor or hospital consultant (or planned to) to discuss the information they got from the Helpline
- 17% had decided to stay on the same drug treatment
- 15% had changed their diet and/or started exercising more
- 14% had changed drug treatment they felt was better for them.

All respondents were asked about changes in their knowledge and confidence as a result of the call. The 448 respondents who filled out a form after four weeks were also asked about whether they had taken any action.

### 6.1 Improvements in knowledge

Most respondents indicated their knowledge had increased as a result of the contact with NOS. Chart five below illustrates these changes for people enquiring for themselves.

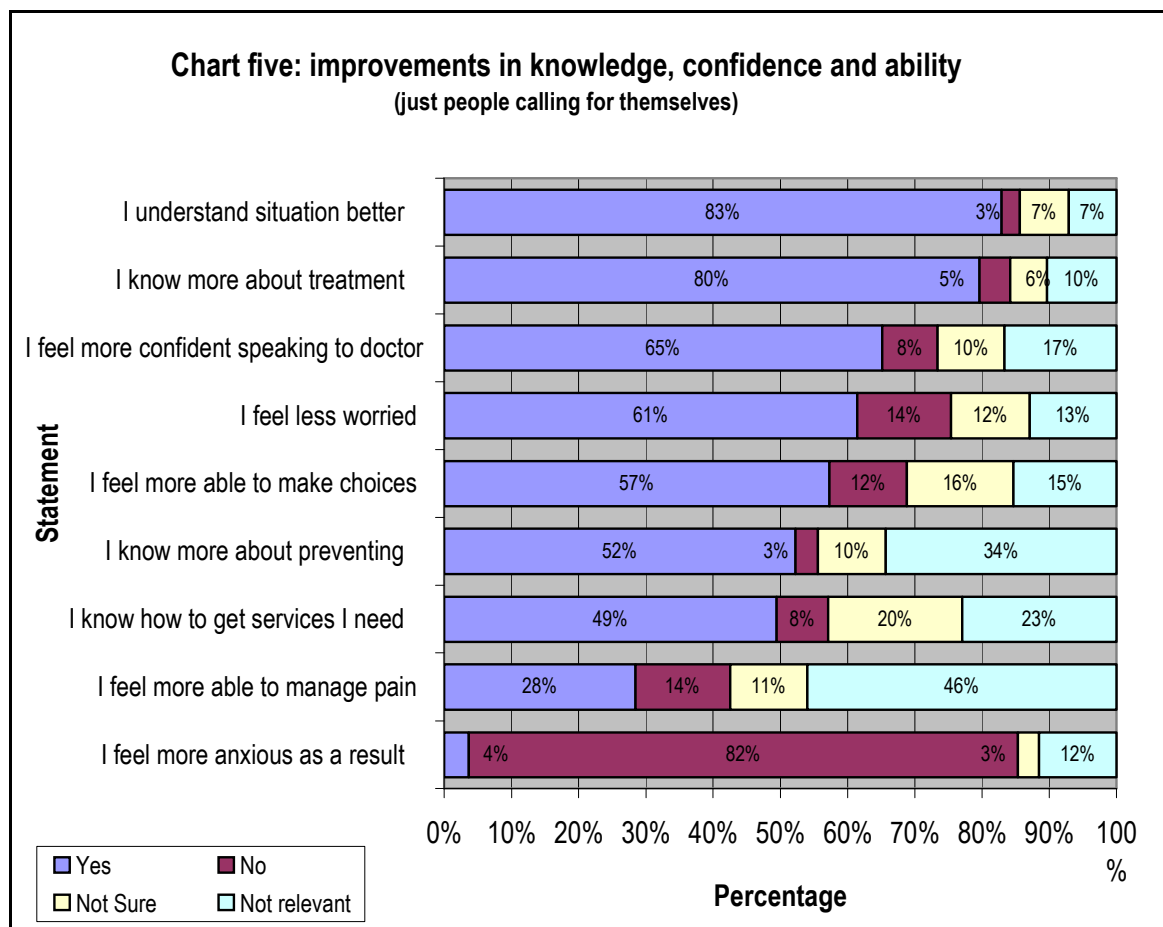
#### People enquiring for themselves

Questionnaire respondents who enquired about themselves reported the following changes in their knowledge:

- 83% (n=496) understood their situation better
- 79% (n=475) knew more about treatment for osteoporosis
- 52% (n=390) knew more about preventing osteoporosis
- 48% (n=398) knew how to get the services they needed.

There were no significant effects on knowledge after time had elapsed; those responding to a questionnaire a week after their contact with NOS rated their knowledge in a similar way to those responding four weeks later. There were also no differences between user type and changes in knowledge.

Of the 15 interview respondents who had called about themselves, all but four said their knowledge had increased. These four explained that they had not expected their knowledge to increase, mostly because NOS had just confirmed what they already knew.



### People enquiring about someone else

Professionals and those enquiring about a family member or friend (51 people in total) also reported similar increases in knowledge:

- 78% (n=36) knew more about treatment for osteoporosis
- 71% (n=34) knew more about osteoporosis generally
- 43% (n=30) knew more about preventing osteoporosis.

Of the five interview respondents calling on behalf of someone else, four said their knowledge had increased. The fifth explained that they were not expecting to be more knowledgeable following the call.

## 6.2 Reduced anxiety

Contacting NOS makes many users feel less worried. For many of the users making enquiries for themselves (62%, n=439), the contact with the Helpline made them feel

less anxious. For those enquiring on behalf of someone else, a similar number (60%, n=32) felt less worried after the contact. Some respondents explained this:

- 'The people I spoke to were really helpful, especially the last call when I was feeling really desperate. She really reassured me and made me feel so much better'.
- 'Had I not had access to your Helpline, I would still feel anxious as a result of diagnosis. Instead I feel confident ... that it isn't necessarily as bad as I thought'.

However, 14 of those enquiring on their own behalf (4%, n=384) and three of those enquiring about someone else (n=39) said they felt more anxious after the contact. Although no respondents explained this, one perhaps got close by explaining that knowing a lot of detail about something might make her worried. It may also be that some people contact the Helpline with expectations that the helpline cannot meet; for example, an enquirer might hope the Helpline will confirm they need treatment when this is not the case.

#### **Case example: feeling reassured**

John<sup>6</sup> called NOS once, on behalf of his wife, who was at risk of osteoporosis. He reported being extremely satisfied with the call. He felt the nurse he spoke to was both understanding and non-patronising, and made him feel less worried about the future; 'she indicated things wouldn't be as bad as I thought'. He reported having tried to get information from the medical profession, but felt that they were not that interested in prevention.

As a result of the call John reported that he and his wife had discussed the information, and thought about what they would do. Some of the information they will keep for the future, including looking into scanning possibilities. They have also changed their diets, including increasing their calcium intake.

Eleven of the 20 interviewees reported feeling reassured at the end of the call. Some of these said it had made them happier with their treatment choices. One reported that 'it had been totally on my mind. Ringing the Helpline put my mind so much at rest... they were the right people to talk to. I'm back in control.' For one interviewee though, the reassurance had been short-lived and they felt worried again a short time after the call. For several interviewees, they had not required reassurance, as they had just wanted information.

### **6.3 Increased confidence and ability**

Many users felt that their confidence and ability to cope had increased following their contact with the Helpline.

#### **To deal with own situation**

Many of the people contacting the Helpline on their own behalf felt more able to manage their situation as a result of the enquiry:

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<sup>6</sup> All respondent names have been changed

- 57% (n=431) said they felt more able to make choices about their treatment<sup>7</sup>
- 28% (n=377) said they felt more able to manage their osteoporosis-related pain.

### **To support others**

Three quarters (75%, n=32) of the people enquiring about a family member or friend said they felt more able to support them as a result of their contact with NOS.

Four out of five of the respondents who were health professionals felt more able to treat/support their patients/clients with osteoporosis.

### **Increased confidence in talking to health professionals**

Of the people enquiring about themselves, 66% (n=437) felt more confident speaking to their doctor or other health professional about osteoporosis.

#### **Case example: the importance of confidence**

Judith<sup>8</sup> had called the Helpline to thank NOS staff. She had called NOS more than 11 times over the last 18 months to get advice and support in her campaign to get drug treatment for herself.

She described NOS as 'endlessly encouraging and helpful'. Initially NOS staff gave her the confidence that she had a case. Having first read the NICE guidelines as to who was eligible for treatment she had felt her situation was hopeless; she fell outside the age range normally prescribed the drug.

This, in part, gave her the confidence to fight her case. She fought to get a scan, worked to 'wear down' her consultants, went to her MP, got the backing of her GP. Judith explained that the information from NOS had helped her argue her case with all these people. NOS also gave her advice about media campaigning.

Judith was finally successful and is being prescribed the medication.

## **6.4 Action taken**

Many respondents reported taking action at least in part because of their enquiry to the Helpline. Chart six below illustrates the most common actions taken.

The 448 respondents receiving a questionnaire four weeks after their contact with the Helpline were asked if they had taken action. More than two thirds of those responding (68%, n=371) said they had taken some form of action. One explained that:

*I was able to make a decision myself through the information I was given... it makes such a difference to talk things through with someone who actually knows what they are talking about.*

<sup>7</sup> It is not possible to match the outcomes to presenting needs; for example, not everyone will have called about treatment choices.

<sup>8</sup> All respondent names have been changed

For some, just having information was enough; 'information is all when you are dealing with something'. Those who have not taken action may still do so in the future. One interviewee explained that 'I now know what to be aware of and what to do in the future.'

Action taken fell into the following categories:

- Further contact with the medical profession
- Decisions regarding treatment
- Taking preventative action
- Supporting others
- Getting further support from NOS.

### **Further contact with medical profession**

Of the 400 people enquiring about themselves and answering questionnaire four, many said they had had some further contact with their doctors or nurses as a result of the call:

- 27% had met with their doctor or hospital consultant (or planned to) to discuss the information they got from the Helpline. A further 4 had met with their practice nurse (or planned to) for the same reason, and one contacted a pharmacist.
- 7% (29) had asked their doctor for tests.

#### **Case example: going back to the doctor**

Marion<sup>9</sup> has osteopenia, caused by the medication she has to take for another medical condition. She reports that her doctors had all been excellent, but that her GP didn't know much about specific treatments, and her consultant was very busy.

She phoned NOS once, and also called a breast cancer line. The NOS nurse reassured her, made her feel more confident in her treatment, and more confident to ask for some additional tests. Using the information from both Helplines she also managed to get to see her oncologist several months earlier to discuss her medication and their potential side effects. She had also started taking load-bearing exercise as a result of the call.

Marion also described how she had assumed some pain she was experiencing was due to osteoporosis. Following a discussion of this with the NOS nurse she is now thinking of going back to the doctor to check.

### **Decisions regarding treatment**

The information given by NOS had enabled some users to make decisions about their treatment.

Of the 400 people enquiring about themselves and answering questionnaire four, 123 had made informed decisions regarding their treatment:

- 14% (54) had changed drug treatment they felt was better for them
- 17% (69) had decided to stay on the same drug treatment.

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<sup>9</sup> All respondent names have been changed

One respondent said that following their call, they 'went ahead with dental treatment reassured about the current thinking about Fosamax.'

#### Case example; decisions regarding treatment

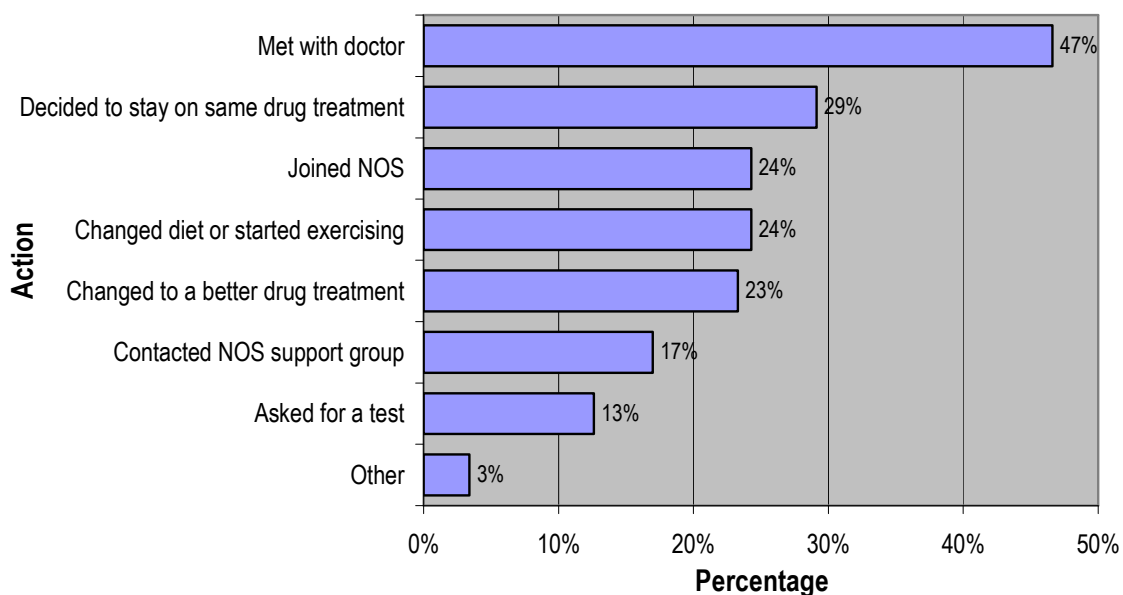
Jane<sup>10</sup> is the parent of a child who had been recently diagnosed with osteoporosis and has other medical conditions. She had been told her child couldn't take medication for osteoporosis as it would interfere with their other medication.

Jane called NOS to find out more about osteoporosis generally ('I wanted anything they could tell me') and to get a second opinion regarding the medication. The NOS nurse felt the child should be able to take both medications, so Jane raised this with her doctor next time she saw them. The doctor agreed and the child is now on both medicines and so far doing well. The NOS nurse also gave the caller ideas as to how to get the child to take the unpleasant tasting medicine, which she found really helpful.

She says that the call made her feel 'more positive' and was 'practical and helpful'. Jane reported that 'I might not have pursued that without that call to NOS'.

One interviewee was told by NOS that they could probably take a lower dose of drugs than had been prescribed, if they changed their diet. After considering this, the respondent chose not to change, as they thought the doctor might have had other reasons for their initial recommendation. Another interviewee still felt unsure about what to do after their call to NOS, but wasn't sure that the nurse could have done anything differently.

Chart six: action taken by people calling about themselves (n=206)



<sup>10</sup> All respondent names have been changed

### **Taking preventative action**

Some of those who enquired about themselves have taken preventative action as a result of their contact with NOS. 15% (n=400) had changed their diet and/or started exercising more. One interviewee explained that since calling NOS she had:

*Put into practice what they told me: things to eat, foods high in calcium. Also, I am now aware that high fibre stops calcium absorption. So now I try to phase the eating of calcium and fibre to increase absorption.*

### **Helping others**

Of those filling out questionnaire four, 32 had called about a family member or friend, and four professionals called about patients. Of these people:

- 9 said they had since helped their family member/friend deal with their osteoporosis or risk of osteoporosis
- 2 of the professionals said they had improved the way they support patients/clients with osteoporosis. One had modified their risk assessment for osteoporosis.

Of the professionals interviewed, one had changed their recommendations regarding prescribing, and the other had passed information onto their clients.

### **Getting further support from NOS**

Of the 400 people enquiring about themselves and filling out questionnaire four, 45 had requested further support through NOS:

- 10% (38) had joined the National Osteoporosis Society
- 4% (17) had contacted a National Osteoporosis Society support group
- Of these, nine had done both.



## **7. Summary and recommendations**

### **7.1 Summary**

NOS Helpline are providing an excellent service. They have a loyal customer base, which rates the service very highly. Almost all respondents said they were satisfied or very satisfied with the way their enquiry had been dealt with, felt the nurses were knowledgeable and gave them information that was easy to understand.

The service could improve in terms of ease of getting through by phone, and the accessibility of the service to certain groups, particularly men and people from ethnic minorities. Some users wanted more information from their enquiry.

The findings on user satisfaction are very similar to those found by the two previous service evaluations<sup>11</sup>. The 1997 Helpline Audit also found that few men or people from ethnic minorities were using the service.

For some people with osteoporosis, NOS is providing an essential specialist service that fills a gap and backs up the service provided by the NHS.

There is good evidence of significant outcomes for users in terms of improved knowledge, confidence and ability and reduced anxiety. Many have taken some positive informed action following their contact with the Helpline. The 1997 Helpline Audit also found that many users had taken action following their enquiry.

### **7.2 Recommendations**

#### **Accessibility of the service**

NOS should consider extending their opening hours and/or providing more nurses. NOS might wish to survey users about the various options for deploying extra resources.

NOS might also consider:

- how to attract more users from ethnic minorities
- how to attract more men to the service
- investigating why letter-writers appear to be less satisfied with the service
- whether email users should be sent more written information.

Currently NOS do not get demographic information on email and letter users. NOS might consider whether this information is important, and if so, how it might be obtained.

#### **Mode of contact**

NOS should consider the relative importance of email to their service. Only about 11% of NOS' Helpline contacts are by email, but almost 50% of the users in this survey had access to the Internet. Use of email could therefore expand.

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<sup>11</sup> *NOS Helpline Audit, 1997; NOS Helpline Survey 2002*, Helen Lancaster Research Ltd

Allowing people to write to the service may be a relatively inefficient use of the nurses' time. However, offering a range of ways to contact the service does increase access, as the different ways attract slightly different audiences. Also, letter-writers are much less likely to have access to the Internet and may not be able to email.

If more users are to access NOS information by email and the Internet, NOS might consider:

- Encouraging repeat callers to use email
- Other ways of encouraging users to use email – one option might be having the email address as the first option on the website
- NOS might also consider ways to develop the website. For example a 'frequently asked questions' section.

A quarter of respondents wanted to clarify something they had heard about in the media. There might be potential to exploit this via the website and divert people from the phone line.

### **Repeat users**

Most respondents in this survey had used the service more than once. NOS could consider whether this can be used to their advantage. For example, NOS could consider whether there would be any benefits of keeping caller records, so the nurse could refer to them rather than going through some questions again each time. It would also give data on repeat usage and reduce the likelihood that repeat users are distorting the demographic picture of the user group as a whole.

### **The role of the NHS**

NOS could consider using the findings in this survey to add weight to its campaign to get osteoporosis included in the GP contract.

### **Content of contact**

NOS should consider exploring further:

- Issues of consistency within and between NOS literature and the Helpline.
- Ways to increase the numbers of users getting all the information they need from their enquiry and from the written information.
- Whether there is anything to be done to reduce the anxiety of people who call.

## **8. Appendices**

### **8.1 Appendix one – interviews**

#### **Details on process**

All interviewees had previously given consent to be called. Interviews took on average 15 minutes and were semi-structured. Calls were made at a range of times during the day, but were all made between 9am and 6pm.

#### **Sampling matrix**

The NOS nurses asked all callers for two weeks whether they would consent to be interviewed. This resulted in 131 people giving consent. Of these, a sample of 40 people was chosen. The sample was stratified according to the known variables that it was felt might affect the outcomes for the user. The sample included:

- All age ranges
- Men and women
- People with osteoporosis, osteoporosis and fractures and osteopenia
- People calling about family or friends with osteoporosis and people wanting to prevent osteoporosis
- Professionals
- NOS members and non members
- People whose call to the Helpline had been of a variety of lengths.

The sample was stratified initially to get numbers proportional to those found in the whole population. Whole population data was obtained from the NOS 2005 annual report. Where data didn't exist, we used the whole consenting sample as reference. We then biased the sample slightly to favour smaller groups (for example, men and people aged 36-45), to ensure at least two from each group were interviewed. We also increased the numbers from groups where we felt there may be rich sources of outcomes:

- Young people with osteoporosis
- People with a diagnosis of osteoporosis and/or fractures
- NOS members
- People who had made longer calls.

#### **Actual respondents**

The 20 interviewees comprised:

- 4 men, 16 women
- 10 people with osteoporosis, of whom 4 also had fractures
- 5 people wanting to prevent osteoporosis, including 3 with osteopenia
- 3 family/friends of people with osteoporosis, and 2 professionals
- 10 NOS members
- People who had made calls of a range of lengths, from under 5 mins to over 20
- People aged from 36 to over 85, with the largest group being 56-75.

The interviews also revealed the following information about them:

- 8 had called the Helpline only the once. 4 had called the Helpline more than 11 times; one almost 30.
- Almost all were extremely satisfied with the service they had received.

- Most had called for general information on osteoporosis and/or drug treatments. Some had also called to get help in understanding what their doctors had told them and/or about lifestyle changes to prevent osteoporosis. A couple had called for information about pain management or coping with fractures.

## 8.2 Appendix two - NOS evaluation interview schedule 2006

Respondent number \_\_\_\_\_ Interview date \_\_\_\_\_

### Notes:

- Dial 141 before all calls
- Do not mention purpose of call before speaking to the right person

### Introduction:

- My name is xxx, and I'm from Charities Evaluation Services. I have been asked by the National Osteoporosis Society Helpline to evaluate their work. I am contacting people who have used the Helpline to find out what they thought of the service they received.
- About a month ago you called the National Osteoporosis Society Helpline, and very kindly agreed to be interviewed by me, do you remember?
- IF THEY DON'T REMEMBER THE CALL, THANKS ANYWAY BUT NO INTERVIEW...
- Are you still happy to be interviewed? It should take about 15 minutes
- Is now okay, or would you rather make an appointment for later?
- Excellent, thanks very much. Just to let you know, whatever you tell me is confidential and anonymous; I will report to the National Osteoporosis Helpline on what I find out, but I will not give them details of who said what.
- If there are any questions you would rather not answer, that's fine, just let me know. You can also ask to stop at any time, or ask for a break.
- Do you have any questions you would like to ask me, before we start?

### 1. Service use

The first few questions are just about how you use the service.

#### How many times have you called the Helpline in total?

- Once       Twice       3 times       4 times       5-10 times       More than 11 times

#### Can you tell me why you called the service?

I need to know very briefly why you called the National Osteoporosis Society Helpline. I don't need to know your personal details.

(Prompt if need be, tick all that apply)

I wanted:

- information about drug treatments
- information about diagnostic tests
- General information on osteoporosis
- information about pain management or coping with fractures
- information about other (not NOS) services available
- to be sent literature
- Information on lifestyle changes on how to prevent osteoporosis
- Help in understanding what a doctor has told me

**Other – please describe**

**How satisfied were you with the way your enquiry was dealt with?**

- Extremely satisfied   
  Quite satisfied   
  It was adequate   
  Not very satisfied   
  Not at all satisfied

Comments

**2. What you did with the information**

I'd next like to ask you some questions about what you did with the information you were given.

**Did you feel that your knowledge or understanding changed as a result of the call to the Helpline?**

Possibilities to be aware of:	
around osteoporosis generally	About the options available to me
around my own treatment	about the services available to me
about how to prevent osteoporosis	

If so, how?

Has that made a difference to your life? How?

Have you used that information? How?

**Did you feel differently about yourself/about your diagnosis/the way you work (as appropriate) as a result of the phone call?**

Possibilities to be aware of:	
Less distressed	
Listened to for first time etc	

Has that made a difference to your life? How?

**After the phone call, did you take any action? If so, what?**

Possibilities to be aware of:	
Setting up new osteoporosis services	Spoke to my doctor, using the information given
Been better about adhering to treatment	Changed the way I support by family member with osteoporosis
Changed my lifestyle	Changed my treatment
Improved the way I work with patients with osteoporosis	Contacted another organisation

Can you explain that to me?

How long after the phone call was this?

(for each action) To what extent did the call to the Helpline help you do this?

Has (this action) had any effect on your life? What?

(note; if coming from Q 6 and saying 'no action', need to make a link between this and Q 5, so as to not break the flow. Eg, 'so going back to how you felt about yourself after the call...')

**As a result of the call, do you feel (as appropriate):**

- more able to manage your osteoporosis? Pain? Dealing with professionals?

- more able to work with patients with osteoporosis
- more able to prevent osteoporosis
- more able to support your family member (etc) with osteoporosis?

Can you explain that to me?

Have these changes had any affect on your life? If so, what?

**Have there been any other changes for you as a result of calling the Helpline, that you haven't yet told me about?**

**Overall, how satisfied were you with the service you received?**

- Extremely   
  quite   
  It was ok   
  not very satisfied   
  not at all satisfied

Comments

**Would you like to add any comments about the Helpline before I finish?**

Ending script

- Thanks very much – I've finished my questions now
- Is there anything you'd like to ask me?
- The information you have given me is really important and will be used to help improve the work of the National Osteoporosis Helpline
- I'll be writing a report on my findings later in the year. Would you like me to send you a summary of that report in the post? It wont come until October.
- Take address. If they don't want to give address, suggest they call NOS Helpline and ask to give address to them, and they can send summary report instead.

### 8.3 Appendix three – questionnaire respondents

The table below gives a detailed comparison of the questionnaire respondents' characteristics. Note that user characteristics are only available for callers from NOS data as a whole.

Variable	Questionnaire respondents			2005 Helpline caller <sup>12</sup> (n=11731)
	N value	No. of respondents	Percentage	
Callers	695	633	91%	87%
Email users	695	27	4%	11%
Letter-writers	695	35	5%	2%
Male	674	35	5%	8%
Female	674	639	95%	92%
Ethnicity - white	669	661	99%	97%
Professionals	695	5	1%	3%
Calling for self	695	634	91%	88%
Friends/family	695	46	7%	9%
NOS members	666	436	65%	25%
Diagnosis of osteoporosis	645	526	82%	56%
Osteoporosis with fractures	604	305	51%	17%
Aged 66-75	675	218	32%	39%
Aged over 55	675	574	85%	82%

<sup>12</sup> Compared with data from NOS Helpline annual report 2005

A user evaluation of the  
National Osteoporosis Society Helpline

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September 2006



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# 1. Executive summary

## 1.1 The evaluation

Charities Evaluation Services carried out an evaluation of the National Osteoporosis Society Helpline during 2006. The evaluation focused on what users thought of the service and outcomes for users.

Data was obtained from two main sources, interviews and postal questionnaires. Twenty phone interviews were carried out with people who had used the service. These interviews helped inform the development of short questionnaires, which were sent to 1081 phone, email and letter users of the Helpline. 695 people returned questionnaires. There was a very high response rate of 64% to the questionnaires.

### Overview of the findings

The NOS Helpline is providing an excellent service. It has a loyal customer base, which rates the service very highly. Almost all respondents said they were satisfied or very satisfied with the way their enquiry had been dealt with. Most felt the nurses were knowledgeable and gave them information that was easy to understand. For some people, NOS is providing an essential specialist service that backs up the service provided by the NHS.

The service could improve in terms of ease of getting through by phone, and the accessibility of the service to certain groups, particularly men and people from ethnic minorities. Some users wanted more information from their enquiry.

There is good evidence of significant outcomes for users in terms of improved knowledge, confidence and ability and reduced anxiety. Many have taken some positive informed action following their contact with the Helpline.

## 1.2 Findings

### Service use

#### *Who is using the service*

- Almost all respondents were women, and white
- 83% had a diagnosis of osteoporosis; of these 47% also had fractures
- Nearly two thirds were aged 56 to 75
- Two thirds were NOS members.

#### *How they are using the service*

- Most had contacted the Helpline for themselves
- 91% had phoned, 4% emailed and 5% had written to the Helpline
- Just over half had called the Helpline more than once, 79% less than five times
- Almost half have access to the Internet.

#### *Why they are using the service*

Many had contacted the Helpline to ask for clarification of something:

- A quarter wanted clarification of something they'd heard about in the media

- Almost a third wanted help in understanding what their GP or hospital consultant had told them.

Most respondents wanted information on:

- Drug treatments for osteoporosis (59%)
- General information on osteoporosis (21%)
- Information on exercise and/or diet (20%)
- Information on pain and coping with osteoporosis (17%).

#### *Relationship of NOS to the NHS*

For most respondents, their GPs were a good source of information on osteoporosis and they reported satisfaction with that service. However, for a significant minority, this was not the case:

- One third said they felt their GP was not able to answer their questions about osteoporosis
- 13% said they did not feel able ask their GP if they had any questions
- One third felt there was not enough time within a consultation to ask questions.

#### **What users thought of the service**

Almost all respondents rated the service very highly indeed:

- Almost all were satisfied with the way their enquiry had been dealt with
- Callers felt that nurses had handled their calls well; almost all felt that the nurse had put them at ease, had listened to them and had given them enough time
- All the emailers and letter-writers felt that the nurses had answered their questions and knew the subject well
- Most email users and letter-writers said they didn't mind the wait for a reply
- All respondents said the information they had been given, either by the nurse or through written information, was easy to understand.

However, some callers are finding it hard to get through to the Helpline. A few wanted more written information, and not everyone got all the information they wanted from the enquiry.

#### **Outcomes for users**

Most respondents reported positive changes as a result of their enquiry.

#### *Improvements in knowledge*

Most respondents said that, as a result of contacting the Helpline, they:

- understood their situation better
- knew more about treatment for osteoporosis and preventing osteoporosis
- knew how to get the services they needed.

#### *Reduced anxiety*

Most people felt less worried after contacting the Helpline.

### *Increased confidence and ability to cope*

Many of the people contacting the Helpline for themselves felt more able to manage their own situation as a result of the enquiry:

- Just over half said they felt more able to make choices about their treatment
- Almost a third said they felt more able to manage their osteoporosis-related pain
- Two thirds felt more confident speaking to their doctor or other health professional about osteoporosis.

Of those enquiring about other people, most felt more able to support that person:

- Three quarters felt more able to support their family member or friend
- Most professionals felt more able to treat/support their patients/clients with osteoporosis.

### *Action taken*

Two thirds of those who had called about themselves said they had taken some action:

- 27% had met with their doctor or hospital consultant (or planned to) to discuss the information they got from the Helpline
- 17% had decided to stay on the same drug treatment
- 15% had changed their diet and/or started exercising more
- 14% had changed to a drug treatment they felt was better for them
- 10% had joined the National Osteoporosis Society.

### *Helping others*

A third of the people enquiring about family or friends said they had since helped that person deal with their osteoporosis or risk of osteoporosis. Two of the five professionals said they had improved the way they support patients/clients with osteoporosis.

## **1.3 Recommendations**

**Accessibility of the service:** NOS should consider extending their opening hours and/or providing more nurses. NOS should also consider how to attract more men and more users from ethnic minorities.

**Mode of contact:** NOS should consider the relative importance of email to their service. Only about 11% of NOS' Helpline contacts are by email, but almost 50% of the users in this survey had access to the Internet. Use of email could expand for some users and NOS might consider ways to encourage and support this.

**The role of the NHS:** NOS could consider using the findings in this survey to add weight to its campaign to get osteoporosis included in the GP contract.

**Information and support offered to users:** NOS should consider exploring further ways to increase the numbers of users getting all the information they need from their enquiry and from the written information. They should also consider whether there is anything to be done to reduce the anxiety of people who contact the service.



## **2. Introduction**

### **2.1 The Helpline**

The National Osteoporosis Society (NOS) offers support and information on osteoporosis. Its users are people with osteoporosis and their carers and families, people wishing to prevent osteoporosis and professionals working with people with osteoporosis. Support and information is primarily offered through a telephone Helpline and through local support groups.

The NOS Helpline has been running for 12 years and is based in Bath. The five staff members operate the service Monday to Friday, offering information primarily by phone, but also by email and letter.

### **2.2 The evaluation**

Charities Evaluation Services (CES) was commissioned by NOS in 2006 to undertake a user evaluation of the Helpline. The evaluation focuses on three things:

- user views of the Helpline
- service usage (how and why they are using the Helpline)
- outcomes for people using the Helpline.

The evaluation was undertaken between March and October 2006, drawing its data primarily from interviews and questionnaires. This document reports on the findings of that evaluation.

### **2.3 Summary of this report**

This report is in five sections:

Section two, *The evaluation*, describes how the evaluation was carried out and who the respondents were, and gives the reader guidance in understanding the findings.

Section three, *Use of the service*, describes how, why and how often respondents were using the service.

Section four, *What users thought of the service*, describes user satisfaction with accessibility, call delivery and content of their enquiry.

Section five, *Outcomes for users*, describes what changes there were for users as a result of their enquiry, and what action they took following it.

Section six, *Summary and recommendations*, summarises the findings and makes suggestions for future action by the Helpline.



### **3. The evaluation**

#### **3.1 Evaluation methods**

Data was obtained from two main sources, interviews and questionnaires.

##### **Interviews**

Twenty phone interviews were carried out with a group of people who had telephoned the service a month before. Respondents were chosen using a detailed sampling matrix to ensure a wide range of user types and different experiences of the Helpline were represented. Appendix one contains more details about the interview process, how these people were sampled, and the respondent characteristics. Appendix two gives the interview schedule.

The interviews were carried out before the drafting of the questionnaires, to allow the information from the interviews to shape the questionnaires.

##### **Questionnaires**

The questionnaires were 4 or 5 sides of A4, and comprised quick tick box questions with a few open questions.

##### *Who the questionnaires were sent to*

There were 2368 users of the Helpline during the period 8 May - July 14th 2006. 1081 of these gave consent to take part in the evaluation and were sent questionnaires. 695 were returned.

Overall, 45% of email and phone users gave consent to be sent a questionnaire; 22% of email users and 47% of callers. This relatively low consent rate may be due in part to the methods used; email users had to actively respond to a link in the autoreply of the nurse's email to them. Not all callers were asked during the consent period.

Letter-writers were automatically sent a questionnaire and not asked for consent. Table one overleaf gives a breakdown of consent rates.

##### *Two types of questionnaire*

There were two basic forms of the questionnaire. Both contained the same core questions, but each had some additional questions. 'Questionnaire one' was sent a week after an enquiry and focused on user satisfaction, as respondents were more likely to remember the nature of the contact soon after. As respondents needed time to take action, 'questionnaire four' was sent four weeks after the enquiry, and asked about any action taken. Each questionnaire type was tailored slightly for email, letter and phone users. Appendices 4 and 5 give the two types of questionnaire (for callers).

The questionnaires were sent to different respondent groups. A lower response rate was expected after four weeks, so about 650 questionnaire four were sent out, and about 450 questionnaire one.

Unexpectedly, the response rate for the questionnaires sent four weeks after contact with the service was very similar to those sent a week after the service; previous

evaluations found the questionnaires sent later achieved a lower response rate. Of the 695 respondents, 448 are of questionnaire four, and 247 of questionnaire one.

### *Filters*

The same form was used for people enquiring about themselves, for those enquiring about a family member/friend and for professionals. Filter questions were used to direct the different types of user to the relevant sections.

### *Piloting*

The questionnaires were piloted with almost 40 people, each being given a scenario to help them fill out the questionnaire. The scenarios included a range of user types, with different levels of satisfaction and differing experiences.

### **Response rates**

The response rate was unusually high; 64% overall. Even more unusually, 100% of letter-writers returned their forms. The high response rate may be due to the nature of the relationship with NOS, the use of a freepost envelope and/or the quality of the forms, or another unknown factor. The table below gives the consent and response rates by user type. It also gives the response rates by user type.

**Table one: respondent consent and response rates**

<b>Mode</b>	<b>Callers</b>	<b>Emailers</b>	<b>Letters</b>	<b>Totals</b>
<b>Users during evaluation period</b>	2134	199	35	2368
<b>Numbers giving consent</b>	999	47	N/a	1046
<b>% giving consent</b>	47%	24%	N/a	45%
<b>Numbers sent questionnaire</b>	999	47	35	1081
<b>Numbers returning questionnaire</b>	633	27	35	695
<b>Response rate</b>	63%	57%	100%	64%

### **The respondents**

The 695 respondents were quite similar to the user group as a whole in most characteristics<sup>1</sup>. Respondents were slightly more often white, female callers, making enquires about themselves. However, questionnaire respondents were significantly different from the main user group in that they;

- had a much higher incidence of osteoporosis and fractures
- were much more likely to be members.

Appendix three gives a detailed breakdown of respondent characteristics as compared with the NOS user group as a whole. Note that the data on respondents includes information on email and letter users, unlike the whole user group.

The reason for the differences between the respondents and NOS whole user group is unknown. However, it is possible that NOS members may be more likely to fill out a form for NOS, and those with a higher level of need regarding osteoporosis may have more interest in NOS as an organisation.

<sup>1</sup> Data from NOS Helpline annual report 2005

## 3.2 Understanding this report

### Potential sources of bias

All respondents in this evaluation, both for interviews and questionnaires, were self-selecting, both at the point of giving consent, and again on returning the form. There may be other sources of bias:

- It could be that those most satisfied are more likely to respond to a survey.
- Respondents were more likely to be NOS members.
- Respondents were more likely to have osteoporosis and fractures.
- Not all callers were asked for consent.
- For interviewees, there may be an additional bias towards people who were more available on the phone at home.
- The questionnaires excluded those who cannot read and write English.

While response rates were very high, given these potential areas of bias, caution is needed in generalising these evaluation findings to the whole user group.

### How to read the findings

#### *Who the data refers to*

All the data in the report refers to the whole group of 695 questionnaire respondents, including all user types. Where data refers to a subgroup, or the interviewees, this is stated.

#### *Who was asked each question*

Not all respondents were asked every question. There were some questions that were only asked a week after the person had contacted the service, and some only after four weeks. Also, some user types were only asked certain questions.

#### *Non-respondents*

In most questions, some respondents have chosen not to answer the question, and it cannot be known what answer these non-respondents would have given. These people have been excluded from the data. This means the percentage for each question is calculated over the total number of responses for each question, not the whole user group.

The symbol 'n' is used to denote the number of respondents to that question. To simplify reporting, and where appropriate, the value for n is given in the relevant section heading.

#### *Use of percentages*

Percentages are used for most findings. Actual respondent numbers are also given when they refer to small groups, or are needed for understanding the data. Where actual respondent numbers are very small, percentages are not used, as in these cases percentages can be misleading.

Percentages are not given for the interview respondents, as it is not appropriate to generalise from this small, purposively sampled group. The data from interviews is to add understanding and explanation.



## 4. Use of the service

### Summary of use of the service

The respondents were almost all older, white women. 83% had a diagnosis of osteoporosis; of these 47% also had fractures. Two thirds were NOS members.

Most had enquired for themselves, using the phone. 4% emailed and 5% had written to the Helpline. Almost half had access to the Internet. Just over half had called the Helpline more than once, 79% less than five times

*Many respondents had contacted the Helpline to ask for clarification of something:*

- A quarter wanted clarification of something they'd heard about in the media
- Almost a third wanted help in understanding what their GP or hospital consultant had told them.

*Most respondents wanted information on:*

- Drug treatments for osteoporosis (59%)
- General information on osteoporosis (21%)
- Information on exercise and/or diet (20%)
- Information on pain and coping with osteoporosis (17%).

Most respondents said their GPs were a good source of information for osteoporosis and they reported satisfaction with that service. However, for a significant minority, this was not the case.

The information in this section is drawn from respondents to both questionnaires.

### 4.1 Who is using the service

#### Ethnicity (n=669)

The respondents were overwhelmingly white; 99% described themselves as white or white British. Six (1%) described themselves as Asian or Asian British, and two as other or mixed. No respondents were Black or Black British, but it would be expected that fewer Black people would contact the Helpline as they are less prone to osteoporosis. Table two below compares these statistics with UK national statistics.

**Table two: comparing respondent ethnicity with UK statistics**

	<b>NOS respondents</b>	<b>UK statistics<sup>2</sup></b>
<b>White or white British</b>	99%	91%
<b>Asian or Asian British</b>	1%	5%
<b>Black or Black British</b>	0%	2%
<b>Other or mixed</b>	0%	2%

<sup>2</sup> 2001 census data national statistics online:  
<http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=10150>

These figures are consistent with NOS 2005 statistics on users, showing that 97% of their callers were white.

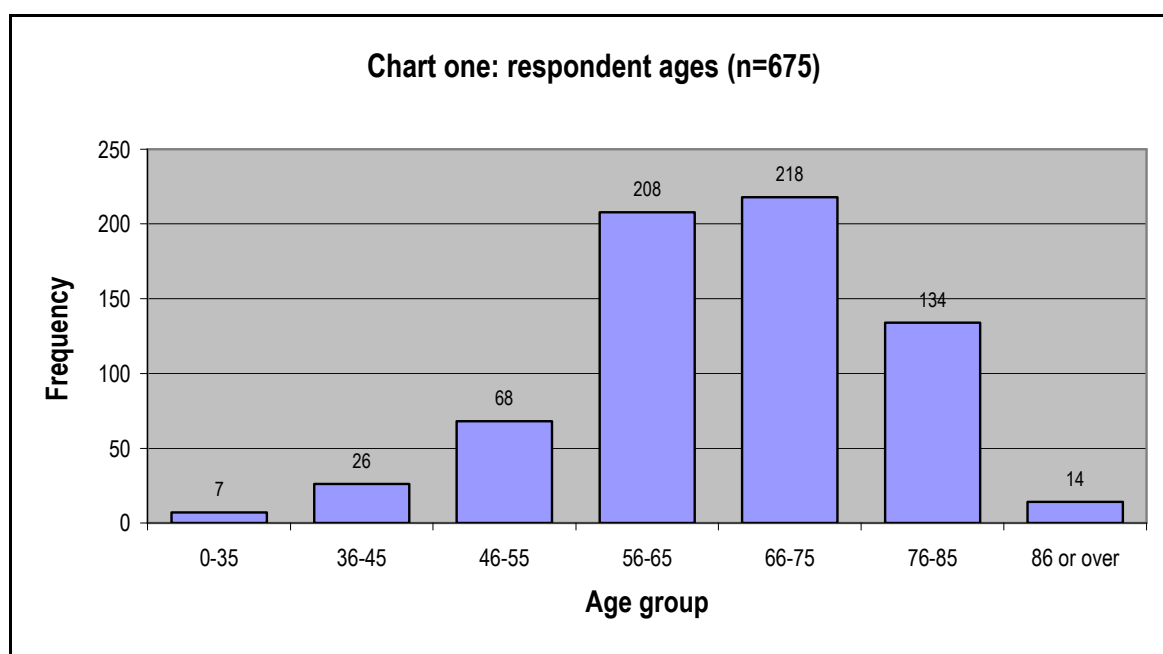
### Gender

Of the 674 who specified their gender, 35 (5%) of respondents were men. The 2005 NOS statistics<sup>3</sup> similarly found 8% of the callers were men.

Given that osteoporosis affects one in two women, and one in five men<sup>4</sup>, one would expect about 30% of users of the service (of those enquiring about themselves) to be men. This figure should perhaps even be a little higher, as amongst the respondent group men were slightly more likely than women to be enquiring about someone else. It is not known whether men use helplines generally more or less than women. Lack of recognition for the disease in men may also lead to fewer men using the service. However, the Helpline could be reaching more men.

### Age (n=675)

The majority of respondents (97%) were aged 36 to 85, with the largest numbers aged 56 to 75 (63%).



### NOS membership (n=666)

Two thirds (65%) of respondents were NOS members; this included two of the five professionals. People with osteoporosis were significantly more likely to become NOS members; 86% (365) of respondents who were NOS members also had a diagnosis of osteoporosis.

<sup>3</sup> NOS Helpline annual report 2005

<sup>4</sup> National Osteoporosis Society *Facts and Figures* booklet

## 4.2 How they are using the service

### Type of user (n=695)

The majority of respondents (91%) had contacted the Helpline for themselves. A few (7%) were enquiring on behalf of a friend or family member, and five (1%) were professionals. Men were slightly more likely to be enquiring on behalf of someone else.

Respondents had a high level of need regarding osteoporosis. The majority (83%, n=645) had a diagnosis of osteoporosis; of these, 47% also had associated fractures.

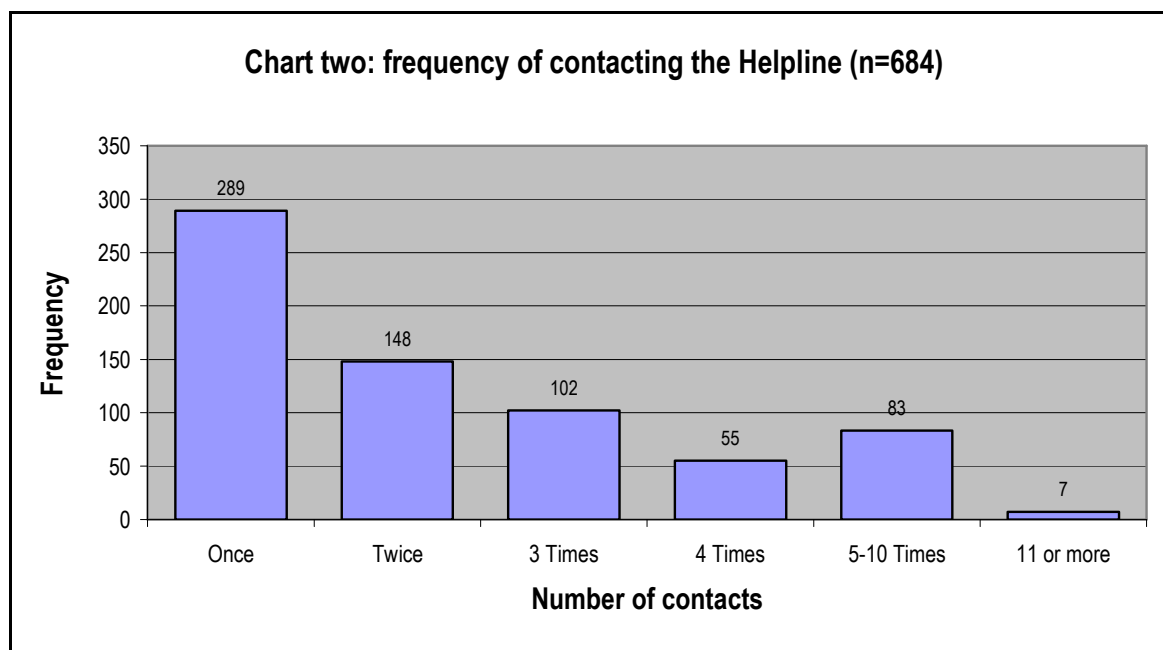
The different modes of contact have attracted slightly different groups of people:

- Email users tended to be younger than callers or letter-writers and were less likely to have a diagnosis of osteoporosis and associated fractures.
- Letter-writers tended to be older than callers or emailers and were more likely to have a diagnosis of osteoporosis and have associated fractures.

### Frequency of contact (n=684)

Just over half of the respondents (58%) had contacted the Helpline more than once. The majority of respondents (79%) reported having contacted the Helpline less than five times; 45% had done so two to four times. These overall figures disguise the following differences:

- Callers had contacted the Helpline more often than email or letter-writers.
- Female respondents had contacted the Helpline more often than men. 60% of men had called just once, compared with 40% of women.
- Respondents who are members of NOS made enquiries much more often than non-members. For example, of the 87 people who said they had contacted the Helpline more than five times in the past, 89% (78) were NOS members.



There was no correlation between how satisfied a user was and how often they contacted the Helpline.

#### *Discussion – men and the Helpline*

Men are less likely to be repeat callers than women. That NOS collect demographic data on all callers, without screening out repeat users, may inflate the numbers of women using the Helpline.

It may be significant that men make enquires less often than women. The reasons for this are unknown, but possibilities include the following:

- They may get all they need within one enquiry and not need to contact the Helpline again.
- Something about the nature of the contact may make them less keen to enquire again.
- They may be disproportionately put off by the difficulties getting through.

#### **Access to the Internet (n=666)**

43% (284) of those who contacted the Helpline by letter or phone said they had access to the Internet. To this figure should be added the 27 email users; this means that 45% of the respondents (n=693) had access to the Internet.

Callers were over twice as likely to have Internet access than letter-writers; only six letter-writers had access to the Internet.

#### **Written material (n=656)**

Most respondents (68%) said they had been sent written material. All respondents said they had read the material, regardless of time elapsed since the contact with NOS.

Letter-writers were most likely to be sent written material, and email users most unlikely. This presumably reflects the ease of sending additional materials to letter-writers.

### **4.3 Why they are using the service**

#### **Clarifying information from a third party (n=695)**

Many respondents had contacted the Helpline to ask for clarification of information they had from a third party; in effect, they wanted a second opinion from NOS. 26% wanted clarification of explanation of something they'd read or heard about in the media. One explained that 'I have been on Fosamax for 10 years. I am concerned about coming off it because of a media report of worse degeneration'.

Almost a third (28%) wanted clarification of something they had heard from their doctor or consultant:

- Almost a fifth (19%) wanted help in understanding what their GP had told them
- 14% wanted help in understanding what their hospital consultant had told them.

### What information was wanted (n=695)

The majority of users (59%) wanted information on drug treatments for osteoporosis. The other most common reasons for enquires were:

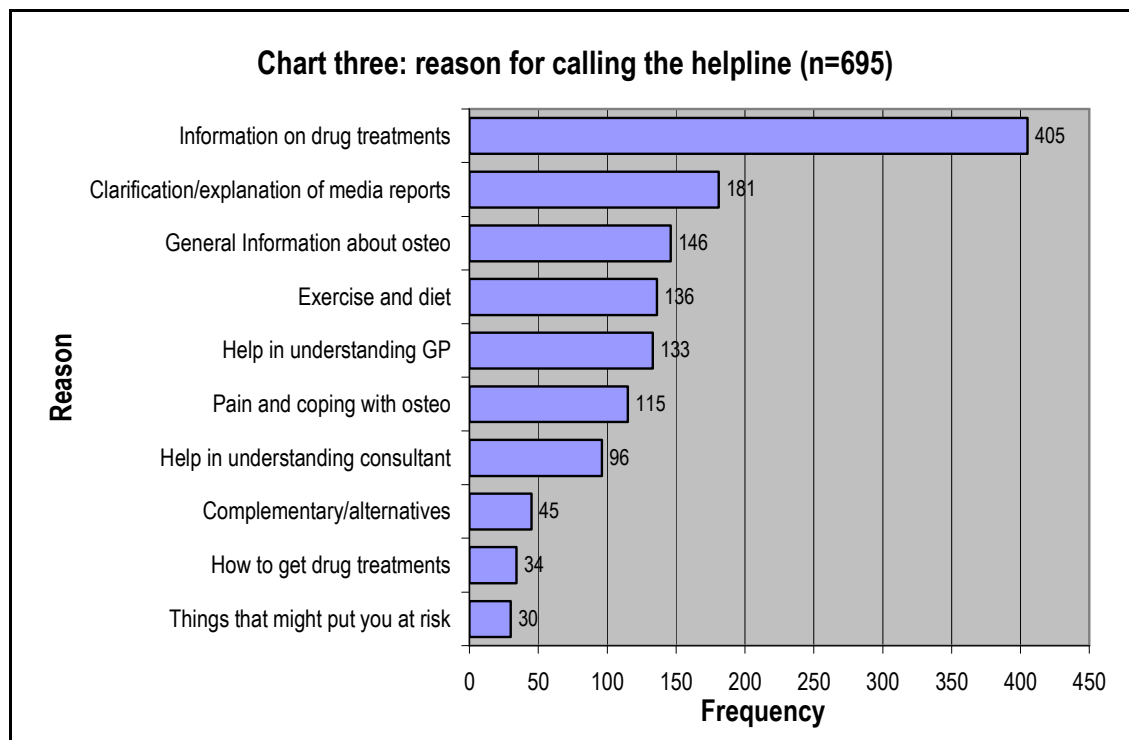
- general information on osteoporosis (21%)
- information on exercise and/or diet (20%)
- information on pain and coping with osteoporosis (17%).

More specialised enquiries included:

- Complementary/alternative therapies (6%)
- How to get drug treatments or tests, including bone density scans (5%)
- Things that might put one at risk of osteoporosis (4%)
- National Osteoporosis Society support groups (4%)
- Other medical issues and their relation to osteoporosis, for example a skin rash (2%, 16)
- Financial help/State benefits (1%, 4).

Two of the professionals mentioned additional specific reasons for their enquiry:

- Clarification of information on the website for use in school and at health days for a support group.
- General advice on developing a risk assessment for osteoporosis.



#### **4.4 Relationship of NOS to the NHS**

All respondents who had called about their own situation were asked about the role of their GP. For most of these, GPs were a good source of information for osteoporosis and they reported satisfaction with that service. However, for a significant minority, this was not the case.

##### **Knowledge of osteoporosis**

The majority of respondents (63%, n=496) said they felt their GP was able to answer their questions about osteoporosis. However, 27% said they felt their GP was not able to answer such questions. This last response was echoed by six of the interview respondents. One explained that, although their doctor had been very good, they 'only knew about one tablet'.

Some respondents in the interviews expressed frustration with the situation. One explained that 'you don't realise until you're in the position [yourself] how difficult it is to obtain the information by conventional routes'.

##### *Patients informing doctors*

Two questionnaire respondents and two interviewees mentioned that they felt they were informing their doctors about osteoporosis. One explained that:

*Having had the results of my scan explained by the Helpline, I was then able to tell my GP what the results meant! I also gave my practice nurse a copy of the diet sheet I obtained from NOS.*

For some of these respondents, their doctors have welcomed the information from NOS. One explained that NOS information had weight with their doctor and consultants, whereas if they presented them with information from the Internet the doctors were more sceptical. However, one questionnaire respondent reported that their consultant felt NOS information was inaccurate.

##### *Trust*

For five of the interview respondents, there was an issue of trust; they didn't trust the NHS as much as NOS. For example, one explained that they felt NOS had no budgetary constraints when giving information about drugs. Three people explicitly said that they had called NOS for a 'second opinion'.

##### *Contradictory information*

Three questionnaire respondents and one interviewee mentioned that it was sometimes problematic that NOS gave different information to their doctors.

##### **Feeling able to ask questions**

Most people (83%, n=543) felt able ask their GP if they had any questions. However, 13% said they did not feel able to ask questions of their GP. One interviewee felt that being able to ask questions was vital; 'you hear such horror stories of people who don't ask questions'.

Feeling unable to ask questions may be due, in part, to lack of consultation time. Although most felt that there was enough time within a consultation to ask questions, this percentage was smaller (64%, n=510). And for 31% of respondents there was not

enough time during a visit to the doctor to ask all the questions they wanted to. A few interview respondents explained that they did not want to trouble their doctor.

Two interviewees said that the fact they could call NOS whenever they needed information, and get 'instant contact' as opposed to having to wait for an appointment, was helpful. Three interviewees commented that they felt the NHS was not interested in prevention.

#### *Using NOS as a preparation*

Two questionnaire respondents and three interviewees commented that they called NOS before seeing their doctors, to enable them to be more informed, and to help them to 'ask more searching questions'. One interviewee explained that this was a practical response to short consultation times, so they could 'go armed, knowing what you want to get out of the appointment time'.

### **Discussion**

A large number of respondents in this survey felt their GP was not able to give them the information they needed. It is possible that NOS users represent a disproportionate number of people unable to get the information they need from their GP, and that this is also reflected in the questionnaire responses.

These findings may reflect an acceptable lack of specialism in GP practice; it may also relate to the absence of osteoporosis in the GP contract.



## 5. What users thought of the service

### Summary of what users thought of the service

*Almost all respondents rated the service very highly indeed:*

- Almost all said they were satisfied or very satisfied with the way their enquiry had been dealt with
- Callers felt that nurses had handled their calls well; almost all felt that the nurse had put them at ease, had listened to them and had given them enough time
- All the emailers and letter-writers felt that the nurses had answered their questions and knew the subject well
- All respondents said the information they had been given by the nurse, or through written information, was easy to understand.

*However,*

- Some callers are finding it hard to get through to the Helpline
- A few wanted more written information
- Not everyone got all the information they wanted from the enquiry.

All respondents were asked about what they thought of the service. Those filling out a form a week after their contact with the service (231 people) were also asked more detailed questions. This section contains data from both the whole group and this subgroup.

### 5.1 Accessibility of the service

#### Ease of getting through by phone

Some callers are finding it hard to get through to the Helpline. Although 90% of callers (n=222) said they found it easy to get through, 9% (18 people) said they did not find it easy. However, this figure was higher amongst those suggesting improvements.

Of the 67 people suggesting improvements, the majority (44) had comments about the accessibility of the service in terms of opening hours and ability to get through. Thirty-one people said that it had been hard to get through to the service; several said they 'almost gave up trying', although some added that it was 'worth persevering' and had much praise for the Helpline. One had written after having no success on the phone. One specified that Mondays in particular were difficult.

NOS staff recently carried out a separate monitoring exercise, asking all callers about how often they had called to get through; 50% said they had no problem getting through, 25% tried twice and 25% tried several or many times. This can be compared to the findings of a recent benchmarking report written for NOS<sup>5</sup>, which found that 50% of calls to the Helpline are not answered.

Various suggestions were made for improving the accessibility of the service, including:

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<sup>5</sup> Catherine Brown (2006), *Helpline Services Benchmarking: Final Report*, NOS

- Extended opening hours (10)
- More staff (6)
- Opening evenings and weekends (2).

In terms of call management, a few additional comments were made:

- Two respondents didn't like the 'mechanical voice' that told them the lines were busy
- Two would have preferred to hear an engaged tone rather than a recorded announcement
- One would have liked to leave a message for a call back.

### **Length of time for email or letter replies**

NOS staff have a target of replying to emails within five working days, and letters within ten. Of the 11 letter-writers who responded to this question, ten said they didn't mind waiting that long. One felt the waiting time was too long. Of the 26 emailers who responded to this question, 21 said they didn't mind the wait, one felt it was too long, and four said they could wait longer.

NOS Helpline staff have expressed concern about the time required to reply to letters and emails. There may be good practice reasons for reducing the waiting time. However, whilst the numbers here are too small to make definitive generalised statements, this data suggests that these respondents were not too concerned about the wait.

## **5.2 Service delivery**

### **Overall satisfaction with the enquiry (n=671)**

Respondents rated the service very highly indeed. Many described the Helpline using words like 'excellent' and 'helpful'. One explained that:

*The service provided by NOS is FAR FAR superior than any of the other various organisations I have had dealings with. You are treated as a responsible intelligent adult. Would that it were so easy everywhere. Have been member for 10 years, and all your information is most welcome. (Respondent's emphasis.)*

Almost all (98%, n=671) respondents said they were satisfied or very satisfied with the way their enquiry had been dealt with; 80% were very satisfied. One explained:

*I found the nurse who answered my questions very professional and helpful - she answered clearly and in terms I could understand. She was very sympathetic and really put my mind at rest. My phone call was superb and I really can't say anything can be improved in the service. Thank you for being there at the end of a phone call.*

Thirteen (2%) said the way their enquiry had been dealt with was adequate, and two said they were not very satisfied. No reasons were given for their dissatisfaction. One did say that the written information they were sent was not enough, and that overall they needed a lot more information from the enquiry. The other reported being more anxious after the call, which may explain their dissatisfaction.

One interview respondent, who had called the Helpline 5-10 times over a long period of time, said that once they had spoken to a nurse who was not very helpful, but had since found the service excellent.

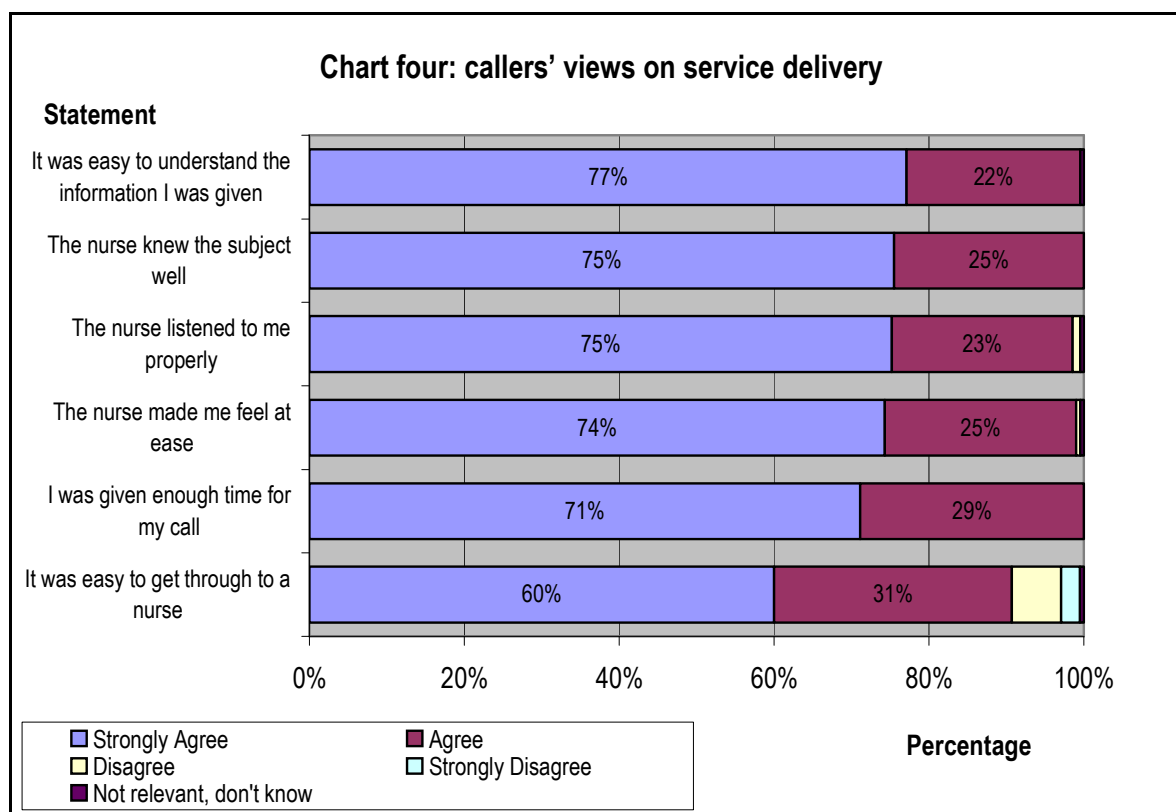
There were some differences in terms of satisfaction and caller type. Letter-writers felt less satisfied with the way their enquiry had been dealt with than callers and emailers. For example, 81% callers said they were very satisfied with the way their enquiry had been dealt with, whereas only 63% (20) of letter-writers said this. The reasons for this are not known.

### Call delivery

Questionnaire one respondents who had phoned the Helpline were asked more detailed questions about how their call was handled.

Callers felt that nurses had handled their calls well; almost all (98%, n=216) felt that the nurse had put them at ease, and a similar number (99%, n=219) felt the nurse had listened to them. Two people felt the nurse had not listened to them well.

Almost all (99%, n=213) said they felt the nurse had given them enough time. However, one respondent did later say they had felt a little rushed. When asked if the service could be improved, one respondent said that this was 'Impossible. It's a hugely reassuring Helpline. The nurses so helpful, no condescension and help with the simplest and most obvious question easily. Thank you.'



## **Getting through to a specialist**

Four interviewees specifically commented that they appreciated getting through to an expert immediately; 'someone who knew what you were talking about – not passed from pillar to post...that impressed me'.

### **5.3 Satisfaction with content**

All callers responding to the question said the information they had been given was easy to understand. Almost all (98%, n=229) felt that the nurse who took their call knew the subject well. One explained that they were:

*Very satisfied. It is reassuring to speak with sensitive authoritative personnel. I would be happy to phone again in the knowledge that my questions would be answered.*

For some, NOS was the only source of information for them. An email respondent explained that:

*The questions I asked were ones from which I had requested information from many professionals; physios, GP's, yoga teachers and none of these people were able to answer. Thanks NOS.*

All the emailers (10) and letter-writers (6) responding to questionnaire one felt that the nurses:

- had answered their questions,
- knew the subject well, and
- gave information that was easy to understand.

However, one respondent felt that the nurse did not know the subject well. Another felt that 'whilst I understand the nurse can't know every illness my other medical conditions were not taken into account when she gave me her answer.'

### **Judging accuracy**

It is not easy for users of the Helpline to judge its accuracy. However, there was a strong feeling from interview respondents that they trusted NOS and felt the information given was accurate; one explained that 'as far as osteoporosis is concerned, I'd check anything with them'. One reported that in their experience, if NOS didn't know the answer they would call them back later with the answer.

### **Written material**

Almost all of those who had been sent written material (96%, n=441) said it was the right amount of information. Three (1%) said it was too much, and 12 (3%) said it was not enough. One of the latter explained that the leaflet she received was 'only an outline/brief summary. I would like to know more about the subject.'

All respondents (n=450) said the information they had been sent was easy to understand.

### **Whether they got the information they wanted**

Most respondents (65%, n=653) said they got all the information they needed. However, a significant number did not get all the information they wanted:

- 27% (174) got most of what they needed
- 5% (35) got some of what they needed
- 16 needed a bit more
- 2 needed a lot more.

Of the two who needed a lot more, no explanations were given as to what would have been helpful. One of these people also said they were dissatisfied with the way their enquiry was dealt with; the other said they were satisfied. Both these people felt the written material they had been sent was not enough.

No differences were found regarding whether or not people got the information they wanted and whether they had been sent written information; those who were sent written information were no more or less likely to say they wanted more information.

Letter-writers were less likely to say they had got everything they wanted from the call. A similar number of emailers (68%) and callers (66%) said they had got everything they needed. Only 48% (12) of letter-writers said this. This figure is based on small numbers and may therefore just be due to chance.

It is worth noting that although letter-writers wanted more information than callers or emailers, letter-writers were more likely to be sent additional written information. It may be that the content of the letter reply to them lacked what they needed.

It may be that NOS would not have been able to provide all these users with all the information they wanted. However, it does seem that some could have been provided with more.

### **Consistency of NOS messages**

Two respondents felt that the Helpline needed to be more consistent in its messages. One explained that 'When I spoke to two different nurses at two different times I received contrary information. This should be avoided if possible as it is very confusing.' The other reported that:

*The fact file "Healthy New Bone" suggested long-term use of Fosamax "might eventually have adverse effects on bone strength and fracture risk." The nurse had not heard this might be the case, although it has since been reprinted in "Osteoporosis News", the NOS magazine. Perhaps the nurses themselves need to be informed of concerns at an earlier stage.*

Another respondent made a request that osteoporosis not be referred to as a disease, explaining that 'it makes me feel contaminated. Condition is an easier term to deal with for me.' This respondent said that the Helpline staff never use the term disease, and that it only occurs in the information packs.

#### **5.4 Recommendations for improvements beyond the Helpline**

Most recommendations from respondents have been integrated into the report findings. However, several respondents made recommendations beyond the remit of the Helpline.

Four people suggested improvements to do with other people:

- Two wanted to be able to get in touch with other people with osteoporosis - it is not known whether a local support group would have been an appropriate option for these people.
- Two wanted to know more about how other people had experienced particular drugs and their side effects.

A few suggestions were made for the NOS magazine:

- More on research (2)
- Less on local groups
- More on men, 'and not just at the back of the mag!'

## 6. Outcomes for users

### Summary of outcomes for users

Most respondents said that, as a result of contacting the Helpline:

- they understood their situation better and knew more about osteoporosis
- they felt less worried.

Many of the people contacting the Helpline for themselves felt more able to manage their own situation as a result of the enquiry:

- Just over half said they felt more able to make treatment choices
- Almost a third said they felt more able to manage pain
- Two thirds felt more confident speaking to their doctor or other health professional about osteoporosis.

Two thirds of those who had called about themselves said they had taken some action:

- A third had met with their doctor or hospital consultant (or planned to) to discuss the information they got from the Helpline
- 17% had decided to stay on the same drug treatment
- 15% had changed their diet and/or started exercising more
- 14% had changed drug treatment they felt was better for them.

All respondents were asked about changes in their knowledge and confidence as a result of the call. The 448 respondents who filled out a form after four weeks were also asked about whether they had taken any action.

### 6.1 Improvements in knowledge

Most respondents indicated their knowledge had increased as a result of the contact with NOS. Chart five below illustrates these changes for people enquiring for themselves.

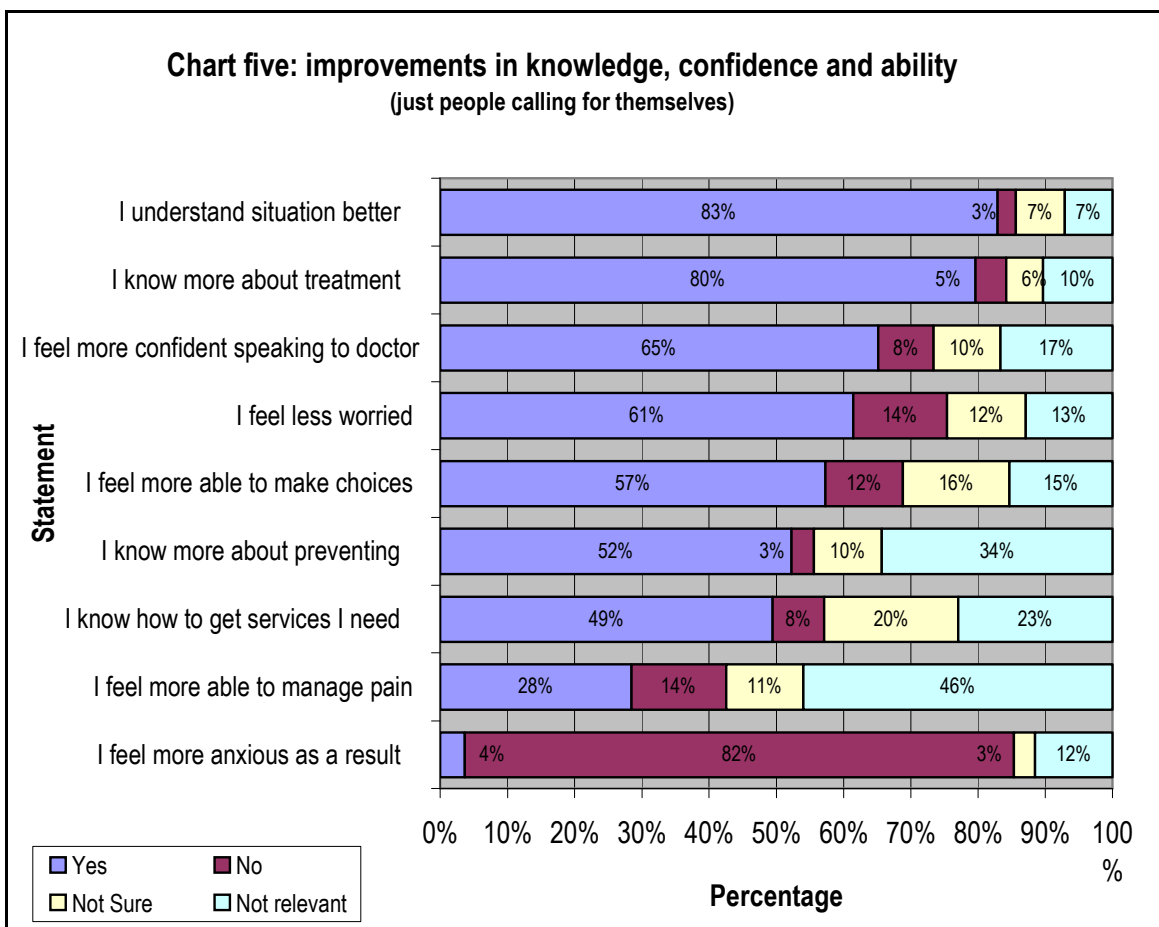
#### People enquiring for themselves

Questionnaire respondents who enquired about themselves reported the following changes in their knowledge:

- 83% (n=496) understood their situation better
- 79% (n=475) knew more about treatment for osteoporosis
- 52% (n=390) knew more about preventing osteoporosis
- 48% (n=398) knew how to get the services they needed.

There were no significant effects on knowledge after time had elapsed; those responding to a questionnaire a week after their contact with NOS rated their knowledge in a similar way to those responding four weeks later. There were also no differences between user type and changes in knowledge.

Of the 15 interview respondents who had called about themselves, all but four said their knowledge had increased. These four explained that they had not expected their knowledge to increase, mostly because NOS had just confirmed what they already knew.



### People enquiring about someone else

Professionals and those enquiring about a family member or friend (51 people in total) also reported similar increases in knowledge:

- 78% (n=36) knew more about treatment for osteoporosis
- 71% (n=34) knew more about osteoporosis generally
- 43% (n=30) knew more about preventing osteoporosis.

Of the five interview respondents calling on behalf of someone else, four said their knowledge had increased. The fifth explained that they were not expecting to be more knowledgeable following the call.

## 6.2 Reduced anxiety

Contacting NOS makes many users feel less worried. For many of the users making enquiries for themselves (62%, n=439), the contact with the Helpline made them feel

less anxious. For those enquiring on behalf of someone else, a similar number (60%, n=32) felt less worried after the contact. Some respondents explained this:

- 'The people I spoke to were really helpful, especially the last call when I was feeling really desperate. She really reassured me and made me feel so much better'.
- 'Had I not had access to your Helpline, I would still feel anxious as a result of diagnosis. Instead I feel confident ... that it isn't necessarily as bad as I thought'.

However, 14 of those enquiring on their own behalf (4%, n=384) and three of those enquiring about someone else (n=39) said they felt more anxious after the contact. Although no respondents explained this, one perhaps got close by explaining that knowing a lot of detail about something might make her worried. It may also be that some people contact the Helpline with expectations that the helpline cannot meet; for example, an enquirer might hope the Helpline will confirm they need treatment when this is not the case.

#### **Case example: feeling reassured**

John<sup>6</sup> called NOS once, on behalf of his wife, who was at risk of osteoporosis. He reported being extremely satisfied with the call. He felt the nurse he spoke to was both understanding and non-patronising, and made him feel less worried about the future; 'she indicated things wouldn't be as bad as I thought'. He reported having tried to get information from the medical profession, but felt that they were not that interested in prevention.

As a result of the call John reported that he and his wife had discussed the information, and thought about what they would do. Some of the information they will keep for the future, including looking into scanning possibilities. They have also changed their diets, including increasing their calcium intake.

Eleven of the 20 interviewees reported feeling reassured at the end of the call. Some of these said it had made them happier with their treatment choices. One reported that 'it had been totally on my mind. Ringing the Helpline put my mind so much at rest... they were the right people to talk to. I'm back in control.' For one interviewee though, the reassurance had been short-lived and they felt worried again a short time after the call. For several interviewees, they had not required reassurance, as they had just wanted information.

### **6.3 Increased confidence and ability**

Many users felt that their confidence and ability to cope had increased following their contact with the Helpline.

#### **To deal with own situation**

Many of the people contacting the Helpline on their own behalf felt more able to manage their situation as a result of the enquiry:

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<sup>6</sup> All respondent names have been changed

- 57% (n=431) said they felt more able to make choices about their treatment<sup>7</sup>
- 28% (n=377) said they felt more able to manage their osteoporosis-related pain.

### **To support others**

Three quarters (75%, n=32) of the people enquiring about a family member or friend said they felt more able to support them as a result of their contact with NOS.

Four out of five of the respondents who were health professionals felt more able to treat/support their patients/clients with osteoporosis.

### **Increased confidence in talking to health professionals**

Of the people enquiring about themselves, 66% (n=437) felt more confident speaking to their doctor or other health professional about osteoporosis.

#### **Case example: the importance of confidence**

Judith<sup>8</sup> had called the Helpline to thank NOS staff. She had called NOS more than 11 times over the last 18 months to get advice and support in her campaign to get drug treatment for herself.

She described NOS as 'endlessly encouraging and helpful'. Initially NOS staff gave her the confidence that she had a case. Having first read the NICE guidelines as to who was eligible for treatment she had felt her situation was hopeless; she fell outside the age range normally prescribed the drug.

This, in part, gave her the confidence to fight her case. She fought to get a scan, worked to 'wear down' her consultants, went to her MP, got the backing of her GP. Judith explained that the information from NOS had helped her argue her case with all these people. NOS also gave her advice about media campaigning.

Judith was finally successful and is being prescribed the medication.

## **6.4 Action taken**

Many respondents reported taking action at least in part because of their enquiry to the Helpline. Chart six below illustrates the most common actions taken.

The 448 respondents receiving a questionnaire four weeks after their contact with the Helpline were asked if they had taken action. More than two thirds of those responding (68%, n=371) said they had taken some form of action. One explained that:

*I was able to make a decision myself through the information I was given... it makes such a difference to talk things through with someone who actually knows what they are talking about.*

<sup>7</sup> It is not possible to match the outcomes to presenting needs; for example, not everyone will have called about treatment choices.

<sup>8</sup> All respondent names have been changed

For some, just having information was enough; 'information is all when you are dealing with something'. Those who have not taken action may still do so in the future. One interviewee explained that 'I now know what to be aware of and what to do in the future.'

Action taken fell into the following categories:

- Further contact with the medical profession
- Decisions regarding treatment
- Taking preventative action
- Supporting others
- Getting further support from NOS.

### **Further contact with medical profession**

Of the 400 people enquiring about themselves and answering questionnaire four, many said they had had some further contact with their doctors or nurses as a result of the call:

- 27% had met with their doctor or hospital consultant (or planned to) to discuss the information they got from the Helpline. A further 4 had met with their practice nurse (or planned to) for the same reason, and one contacted a pharmacist.
- 7% (29) had asked their doctor for tests.

#### **Case example: going back to the doctor**

Marion<sup>9</sup> has osteopenia, caused by the medication she has to take for another medical condition. She reports that her doctors had all been excellent, but that her GP didn't know much about specific treatments, and her consultant was very busy.

She phoned NOS once, and also called a breast cancer line. The NOS nurse reassured her, made her feel more confident in her treatment, and more confident to ask for some additional tests. Using the information from both Helplines she also managed to get to see her oncologist several months earlier to discuss her medication and their potential side effects. She had also started taking load-bearing exercise as a result of the call.

Marion also described how she had assumed some pain she was experiencing was due to osteoporosis. Following a discussion of this with the NOS nurse she is now thinking of going back to the doctor to check.

### **Decisions regarding treatment**

The information given by NOS had enabled some users to make decisions about their treatment.

Of the 400 people enquiring about themselves and answering questionnaire four, 123 had made informed decisions regarding their treatment:

- 14% (54) had changed drug treatment they felt was better for them
- 17% (69) had decided to stay on the same drug treatment.

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<sup>9</sup> All respondent names have been changed

One respondent said that following their call, they 'went ahead with dental treatment reassured about the current thinking about Fosamax.'

#### Case example; decisions regarding treatment

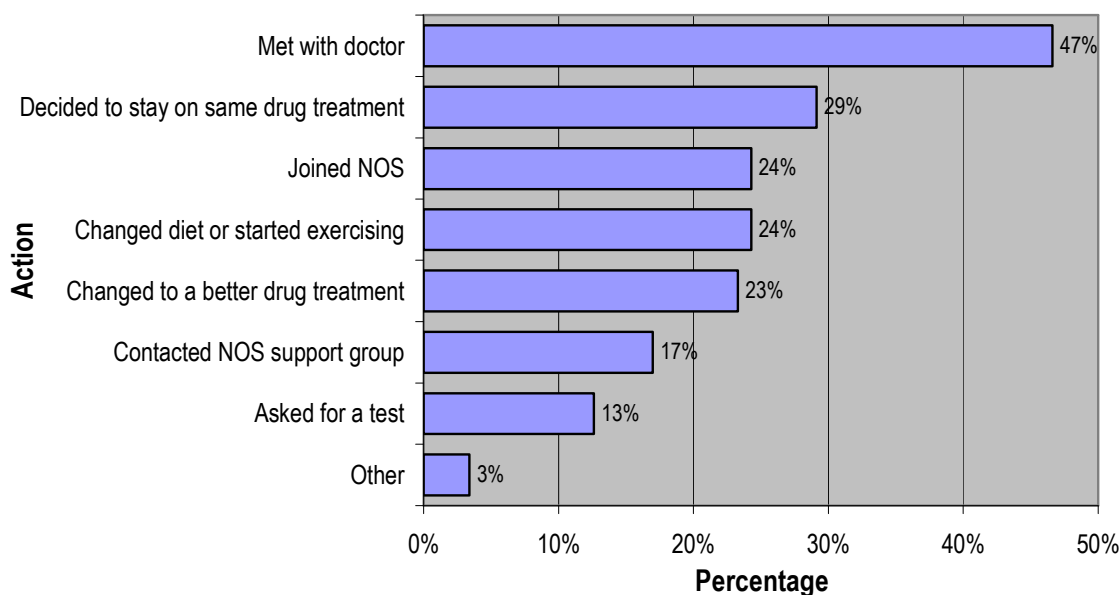
Jane<sup>10</sup> is the parent of a child who had been recently diagnosed with osteoporosis and has other medical conditions. She had been told her child couldn't take medication for osteoporosis as it would interfere with their other medication.

Jane called NOS to find out more about osteoporosis generally ('I wanted anything they could tell me') and to get a second opinion regarding the medication. The NOS nurse felt the child should be able to take both medications, so Jane raised this with her doctor next time she saw them. The doctor agreed and the child is now on both medicines and so far doing well. The NOS nurse also gave the caller ideas as to how to get the child to take the unpleasant tasting medicine, which she found really helpful.

She says that the call made her feel 'more positive' and was 'practical and helpful'. Jane reported that 'I might not have pursued that without that call to NOS'.

One interviewee was told by NOS that they could probably take a lower dose of drugs than had been prescribed, if they changed their diet. After considering this, the respondent chose not to change, as they thought the doctor might have had other reasons for their initial recommendation. Another interviewee still felt unsure about what to do after their call to NOS, but wasn't sure that the nurse could have done anything differently.

Chart six: action taken by people calling about themselves (n=206)



<sup>10</sup> All respondent names have been changed

### **Taking preventative action**

Some of those who enquired about themselves have taken preventative action as a result of their contact with NOS. 15% (n=400) had changed their diet and/or started exercising more. One interviewee explained that since calling NOS she had:

*Put into practice what they told me: things to eat, foods high in calcium. Also, I am now aware that high fibre stops calcium absorption. So now I try to phase the eating of calcium and fibre to increase absorption.*

### **Helping others**

Of those filling out questionnaire four, 32 had called about a family member or friend, and four professionals called about patients. Of these people:

- 9 said they had since helped their family member/friend deal with their osteoporosis or risk of osteoporosis
- 2 of the professionals said they had improved the way they support patients/clients with osteoporosis. One had modified their risk assessment for osteoporosis.

Of the professionals interviewed, one had changed their recommendations regarding prescribing, and the other had passed information onto their clients.

### **Getting further support from NOS**

Of the 400 people enquiring about themselves and filling out questionnaire four, 45 had requested further support through NOS:

- 10% (38) had joined the National Osteoporosis Society
- 4% (17) had contacted a National Osteoporosis Society support group
- Of these, nine had done both.



## **7. Summary and recommendations**

### **7.1 Summary**

NOS Helpline are providing an excellent service. They have a loyal customer base, which rates the service very highly. Almost all respondents said they were satisfied or very satisfied with the way their enquiry had been dealt with, felt the nurses were knowledgeable and gave them information that was easy to understand.

The service could improve in terms of ease of getting through by phone, and the accessibility of the service to certain groups, particularly men and people from ethnic minorities. Some users wanted more information from their enquiry.

The findings on user satisfaction are very similar to those found by the two previous service evaluations<sup>11</sup>. The 1997 Helpline Audit also found that few men or people from ethnic minorities were using the service.

For some people with osteoporosis, NOS is providing an essential specialist service that fills a gap and backs up the service provided by the NHS.

There is good evidence of significant outcomes for users in terms of improved knowledge, confidence and ability and reduced anxiety. Many have taken some positive informed action following their contact with the Helpline. The 1997 Helpline Audit also found that many users had taken action following their enquiry.

### **7.2 Recommendations**

#### **Accessibility of the service**

NOS should consider extending their opening hours and/or providing more nurses. NOS might wish to survey users about the various options for deploying extra resources.

NOS might also consider:

- how to attract more users from ethnic minorities
- how to attract more men to the service
- investigating why letter-writers appear to be less satisfied with the service
- whether email users should be sent more written information.

Currently NOS do not get demographic information on email and letter users. NOS might consider whether this information is important, and if so, how it might be obtained.

#### **Mode of contact**

NOS should consider the relative importance of email to their service. Only about 11% of NOS' Helpline contacts are by email, but almost 50% of the users in this survey had access to the Internet. Use of email could therefore expand.

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<sup>11</sup> *NOS Helpline Audit, 1997; NOS Helpline Survey 2002*, Helen Lancaster Research Ltd

Allowing people to write to the service may be a relatively inefficient use of the nurses' time. However, offering a range of ways to contact the service does increase access, as the different ways attract slightly different audiences. Also, letter-writers are much less likely to have access to the Internet and may not be able to email.

If more users are to access NOS information by email and the Internet, NOS might consider:

- Encouraging repeat callers to use email
- Other ways of encouraging users to use email – one option might be having the email address as the first option on the website
- NOS might also consider ways to develop the website. For example a 'frequently asked questions' section.

A quarter of respondents wanted to clarify something they had heard about in the media. There might be potential to exploit this via the website and divert people from the phone line.

### **Repeat users**

Most respondents in this survey had used the service more than once. NOS could consider whether this can be used to their advantage. For example, NOS could consider whether there would be any benefits of keeping caller records, so the nurse could refer to them rather than going through some questions again each time. It would also give data on repeat usage and reduce the likelihood that repeat users are distorting the demographic picture of the user group as a whole.

### **The role of the NHS**

NOS could consider using the findings in this survey to add weight to its campaign to get osteoporosis included in the GP contract.

### **Content of contact**

NOS should consider exploring further:

- Issues of consistency within and between NOS literature and the Helpline.
- Ways to increase the numbers of users getting all the information they need from their enquiry and from the written information.
- Whether there is anything to be done to reduce the anxiety of people who call.

## **8. Appendices**

### **8.1 Appendix one – interviews**

#### **Details on process**

All interviewees had previously given consent to be called. Interviews took on average 15 minutes and were semi-structured. Calls were made at a range of times during the day, but were all made between 9am and 6pm.

#### **Sampling matrix**

The NOS nurses asked all callers for two weeks whether they would consent to be interviewed. This resulted in 131 people giving consent. Of these, a sample of 40 people was chosen. The sample was stratified according to the known variables that it was felt might affect the outcomes for the user. The sample included:

- All age ranges
- Men and women
- People with osteoporosis, osteoporosis and fractures and osteopenia
- People calling about family or friends with osteoporosis and people wanting to prevent osteoporosis
- Professionals
- NOS members and non members
- People whose call to the Helpline had been of a variety of lengths.

The sample was stratified initially to get numbers proportional to those found in the whole population. Whole population data was obtained from the NOS 2005 annual report. Where data didn't exist, we used the whole consenting sample as reference. We then biased the sample slightly to favour smaller groups (for example, men and people aged 36-45), to ensure at least two from each group were interviewed. We also increased the numbers from groups where we felt there may be rich sources of outcomes:

- Young people with osteoporosis
- People with a diagnosis of osteoporosis and/or fractures
- NOS members
- People who had made longer calls.

#### **Actual respondents**

The 20 interviewees comprised:

- 4 men, 16 women
- 10 people with osteoporosis, of whom 4 also had fractures
- 5 people wanting to prevent osteoporosis, including 3 with osteopenia
- 3 family/friends of people with osteoporosis, and 2 professionals
- 10 NOS members
- People who had made calls of a range of lengths, from under 5 mins to over 20
- People aged from 36 to over 85, with the largest group being 56-75.

The interviews also revealed the following information about them:

- 8 had called the Helpline only the once. 4 had called the Helpline more than 11 times; one almost 30.
- Almost all were extremely satisfied with the service they had received.

- Most had called for general information on osteoporosis and/or drug treatments. Some had also called to get help in understanding what their doctors had told them and/or about lifestyle changes to prevent osteoporosis. A couple had called for information about pain management or coping with fractures.

## 8.2 Appendix two - NOS evaluation interview schedule 2006

Respondent number \_\_\_\_\_ Interview date \_\_\_\_\_

### Notes:

- Dial 141 before all calls
- Do not mention purpose of call before speaking to the right person

### Introduction:

- My name is xxx, and I'm from Charities Evaluation Services. I have been asked by the National Osteoporosis Society Helpline to evaluate their work. I am contacting people who have used the Helpline to find out what they thought of the service they received.
- About a month ago you called the National Osteoporosis Society Helpline, and very kindly agreed to be interviewed by me, do you remember?
- IF THEY DON'T REMEMBER THE CALL, THANKS ANYWAY BUT NO INTERVIEW...
- Are you still happy to be interviewed? It should take about 15 minutes
- Is now okay, or would you rather make an appointment for later?
- Excellent, thanks very much. Just to let you know, whatever you tell me is confidential and anonymous; I will report to the National Osteoporosis Helpline on what I find out, but I will not give them details of who said what.
- If there are any questions you would rather not answer, that's fine, just let me know. You can also ask to stop at any time, or ask for a break.
- Do you have any questions you would like to ask me, before we start?

### 1. Service use

The first few questions are just about how you use the service.

#### How many times have you called the Helpline in total?

- Once       Twice       3 times       4 times       5-10 times       More than 11 times

#### Can you tell me why you called the service?

I need to know very briefly why you called the National Osteoporosis Society Helpline. I don't need to know your personal details.

(Prompt if need be, tick all that apply)

I wanted:

- information about drug treatments
- information about diagnostic tests
- General information on osteoporosis
- information about pain management or coping with fractures
- information about other (not NOS) services available
- to be sent literature
- Information on lifestyle changes on how to prevent osteoporosis
- Help in understanding what a doctor has told me

**Other – please describe**

**How satisfied were you with the way your enquiry was dealt with?**

- Extremely satisfied     Quite satisfied     It was adequate     Not very satisfied     Not at all satisfied

Comments

**2. What you did with the information**

I'd next like to ask you some questions about what you did with the information you were given.

**Did you feel that your knowledge or understanding changed as a result of the call to the Helpline?**

Possibilities to be aware of:	
around osteoporosis generally	About the options available to me
around my own treatment	about the services available to me
about how to prevent osteoporosis	

If so, how?

Has that made a difference to your life? How?

Have you used that information? How?

**Did you feel differently about yourself/about your diagnosis/the way you work (as appropriate) as a result of the phone call?**

Possibilities to be aware of:	
Less distressed	
Listened to for first time etc	

Has that made a difference to your life? How?

**After the phone call, did you take any action? If so, what?**

Possibilities to be aware of:	
Setting up new osteoporosis services	Spoke to my doctor, using the information given
Been better about adhering to treatment	Changed the way I support by family member with osteoporosis
Changed my lifestyle	Changed my treatment
Improved the way I work with patients with osteoporosis	Contacted another organisation

Can you explain that to me?

How long after the phone call was this?

(for each action) To what extent did the call to the Helpline help you do this?

Has (this action) had any effect on your life? What?

(note; if coming from Q 6 and saying 'no action', need to make a link between this and Q 5, so as to not break the flow. Eg, 'so going back to how you felt about yourself after the call...')

**As a result of the call, do you feel (as appropriate):**

- more able to manage your osteoporosis? Pain? Dealing with professionals?

- more able to work with patients with osteoporosis
- more able to prevent osteoporosis
- more able to support your family member (etc) with osteoporosis?

Can you explain that to me?

Have these changes had any affect on your life? If so, what?

**Have there been any other changes for you as a result of calling the Helpline, that you haven't yet told me about?**

**Overall, how satisfied were you with the service you received?**

- Extremely   
  quite   
  It was ok   
  not very satisfied   
  not at all satisfied

Comments

**Would you like to add any comments about the Helpline before I finish?**

Ending script

- Thanks very much – I've finished my questions now
- Is there anything you'd like to ask me?
- The information you have given me is really important and will be used to help improve the work of the National Osteoporosis Helpline
- I'll be writing a report on my findings later in the year. Would you like me to send you a summary of that report in the post? It wont come until October.
- Take address. If they don't want to give address, suggest they call NOS Helpline and ask to give address to them, and they can send summary report instead.

### 8.3 Appendix three – questionnaire respondents

The table below gives a detailed comparison of the questionnaire respondents' characteristics. Note that user characteristics are only available for callers from NOS data as a whole.

Variable	Questionnaire respondents			2005 Helpline caller <sup>12</sup> (n=11731)
	N value	No. of respondents	Percentage	
Callers	695	633	91%	87%
Email users	695	27	4%	11%
Letter-writers	695	35	5%	2%
Male	674	35	5%	8%
Female	674	639	95%	92%
Ethnicity - white	669	661	99%	97%
Professionals	695	5	1%	3%
Calling for self	695	634	91%	88%
Friends/family	695	46	7%	9%
NOS members	666	436	65%	25%
Diagnosis of osteoporosis	645	526	82%	56%
Osteoporosis with fractures	604	305	51%	17%
Aged 66-75	675	218	32%	39%
Aged over 55	675	574	85%	82%

<sup>12</sup> Compared with data from NOS Helpline annual report 2005