healthwatch
Hampshire

# CIS’ters Survey of Health Needs

## 1 Introduction

CIS’ters was established twenty years ago to support and empower female survivors who were sexually abused as children by a member of their immediate or extended family. Since then it has supported some 1286 survivors. It currently has 359 members, of whom 208 live in Hampshire, Southampton, Portsmouth, and the Isle of Wight. In early February 2015 these women were invited to participate in the CIS’ters’ survey of health needs which was funded by Healthwatch Hampshire. We received 49 responses, a 24% response rate.

## 2 Methods

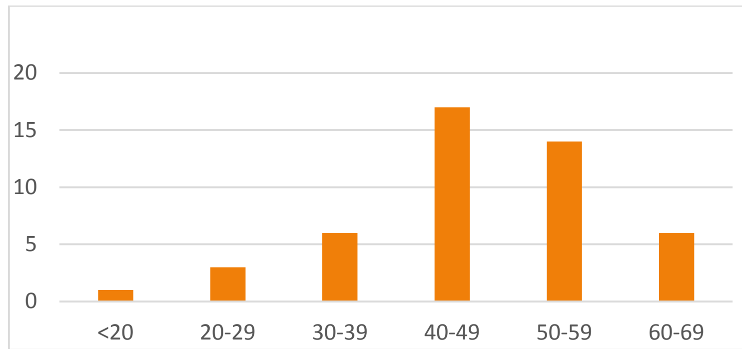
Details of the survey were sent in a postal communication to members. A link to an on-line version administered via Survey Monkey was included. A hard copy was also sent as some members are not comfortable working with electronic media. The voluntary nature of participation was stressed and anonymity was guaranteed. Measures to protect anonymity included ensuring that the IP address of the respondents’ computer would not be retained on the system. Respondents were free to omit any question if they did not want to provide an answer. Hard copies were returned to CIS’ters in a stamped addressed envelope and data was entered to Survey Monkey by CIS’ters’ manager and office worker, neither of whom was involved in analysis.

## 3 Results

### 3.1 Population characteristics

The 49 women who responded to the survey ranged in age from 18-68. Two women did not provide their age. The age distribution for the other 47 is shown in Graph 1. Forty seven women provided details of their ethnic group of whom 44 (94%) were white British. One woman was white Irish, one ‘other white’ and another was mixed race.

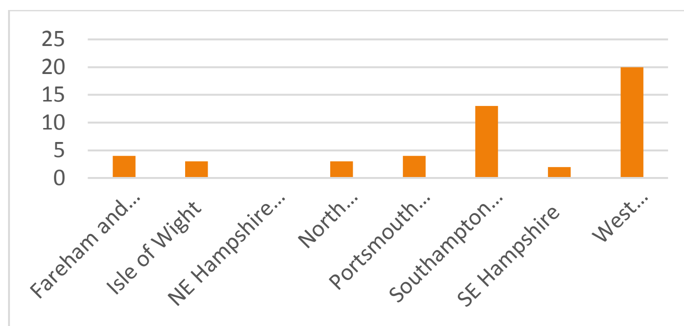
**Figure 1 Age distribution of sample population**




Seventy six percent (n=37) of the women had been pregnant but none had seen a midwife in the last 24 months. Seven of the women had become pregnant as a result of their abuse. Twenty of the women who had been pregnant had experienced at least one miscarriage and 12 had had at least one termination of pregnancy. Six of these women were teenagers when they had their first termination of pregnancy, the youngest being 13 years old. One woman had had a stillbirth. Ten women had experienced fertility difficulties and 4 had made a conscious decision not to have children at the time of the survey– although 2 indicated that this was not a long-term decision.

Graph 2 shows the spread of responses by Care Commissioning Group (CCG). It is not surprising that most of the women live in the area covered by West Hampshire CG as this covers by far the largest geographical area

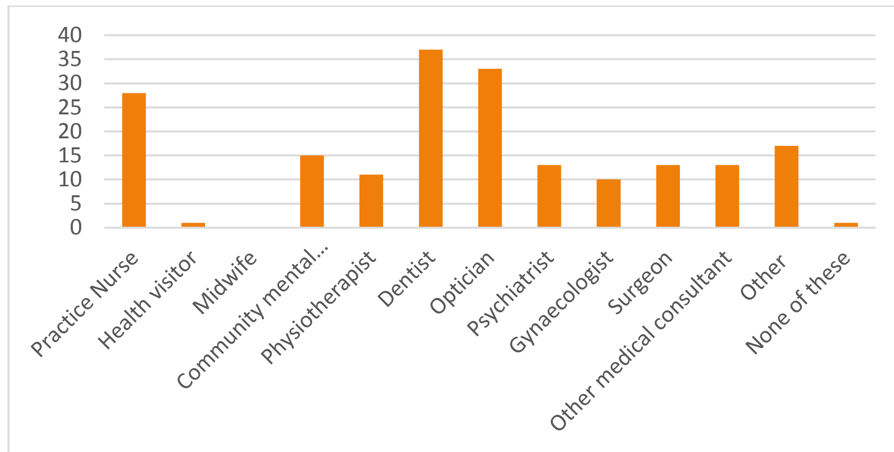
**Figure 2 Responses by CCG**




## 3.2 USE OF HEALTH SERVICES

Only one of the women had not seen her GP in the last 24 months. Twenty eight (57%) of them had seen their GP more than six times in the last 24 months. Other health care professionals accessed in this period are shown in Graph 3.

**Figure 3 Use of health care professionals in last 24 months**




Answers in the 'Other' category included a podiatrist, a specialist nurse, a speech therapist, a radiographer and details of medical or surgical consultants seen. Women also mentioned various types of talking therapy which are covered separately below. This group of women are therefore fairly heavy users of health services and although this is partly explained by the skew to the older age range in this survey population, the particular health needs of survivors have been recognised elsewhere (Itzin 2006).

Overall, women were positive about the care they received as shown in table 1.

**Table 1 Satisfaction with care received from health care professionals**

| **Overall, how would you rate the care you received from these professionals?** | | | | |
|---|---|---|---|---|
| **Answer Options** | **Good** | **Satisfactory** | **Poor** | **Not applicable** |
| **Practice Nurse** | 19 (70%) | 6 (22%) | 1 (4%) | 1 (4%) |
| **Health Visitor** | 2 (13%) | 1 (7%) | 0 | 12 (80%) |
| **Midwife** | 0 | 2 14%) | 0 | 12 (86%) |
| **Community mental health nurse** | 5 (20%) | 4 (16%) | 7 (28%) | 9 (36%) |
| **Physiotherapist** | 5 (28%) | 5 (28%) | 0 | 8 (44%) |
| **Dentist** | 20 (57%) | 11 (31%) | 1 (3%) | 3 (9%) |
| **Optician** | 22 (65%) | 10 (29%) | 0 | 2 (6%) |
| **Psychiatrist** | 7 (32%) | 6 (27%) | 1 (5%) | 8 (36%) |
| **Gynaecologist** | 7 (39%) | 3 (17%) | 0 | 8 (44%) |
| **Surgeon** | 8 (40%) | 5 (25%) | 1 (5%) | 6 (30%) |
| **Other medical consultant** | 3 (20%) | 5 (33%) | 2 (13%) | 5 (33%) |
| **Other** | 7 (39%) | 6 (33%) | 1 (6%) | 4 (22%) |

Where practitioners have been rated 'poor' this is generally by only one or two people and although individual experiences are important, it is not appropriate to extrapolate to services in general on the basis of them. The experience of community mental health nurses is worthy of note. Of the 16 women who had accessed this service, 7 rated it as poor.

One woman's experience of her mental health nurse was *'not compassionate or empathic and almost to the point of bullying and threatening'*. It is evident from comments made by other women that being heard is important. For example one woman commented:

*'The community mental health nurse sees me for 20 minutes every 3 months. She is not interested in listening, just referring me to places'*

Another did not feel believed:

*'A mental health worker made an entry in my notes "Alleges sexual abuse in childhood." If I had experienced being beaten up and robbed in childhood, I am certain "alleges" would not have been included.'*

Whilst health care professionals have guidance on record keeping to which they must adhere, sensitivity to the messages they are conveying to their clients and potential damage to the therapeutic relationship are also important considerations.

## 3.3 Access to Screening Services

Fifty five percent of the women (n=27) had had a cervical smear in the recommended previous 3-5 years. Of the 22 who had not attended, two are not yet aged 25. Another three specifically mentioned having had a hysterectomy and/or lack of a cervix. Several of the women indicated how difficult they find the prospect of having a smear due to triggers or flashbacks experienced. Others mentioned the need for a trusted person and an understanding approach. They needed patience, reassurance and to be put at ease. One woman could have faced a smear if it was done somewhere other than her doctor's surgery and another needed a female practitioner to do it.

Twenty two (46%) women had not yet been invited for a mammogram. Of those who had, 35% (n=17) had attended in the last 3-5 years and 19% had not (n=9). Five women commented on what would make it possible for them to attend, two of whom two were adamant that there was nothing. One was due her mammogram and intended to phone ahead to ask for extra time. Another talked of the need to have someone with her to make sure she could keep herself covered up as much as possible.

Thirty seven women (76%) had attended a dental check in the last year as recommended. Of the 24% of women who had not (n=12), nine added a comment. Issues of trust and continuity arose again:

*'If I had the same dentist every time I needed to go, maybe that could possibly help. Maybe I could get to know the dentist, maybe confide in them. A woman if possible. But I don't get a choice. Different people every time I go. Hence I don't hardly go anymore'*

For a couple of the women, a general anaesthetic is the only thing that makes going to the dentist possible because they cannot tolerate anyone putting something in their mouths. Another needed to know that she would *'feel safe. Not vulnerable'.* Some comments related to dental services in general rather than the issue of accessing services as a survivor. For example cost was an issue for two women and one woman wished she could find a better dentist and one who would send reminders every six months as she had experienced elsewhere.

The vast majority of respondents have attended for an eye test in the last two years (90%, n=44). Of the 5 who had not, 2 admitted to laziness on their part and for another cost was again an issue. One woman said she would go if opticians wore a mask over their nose and mouth. Other women who have attended commented on aspects of seeing an optician that can be difficult for survivors:

*'Opticians are tricky because of darkish room and they stand so close. Make me feel defensive.'*

Someone else noted that they ask for the door to remain open when they see an optician.

## 3.4 Survivors' health needs

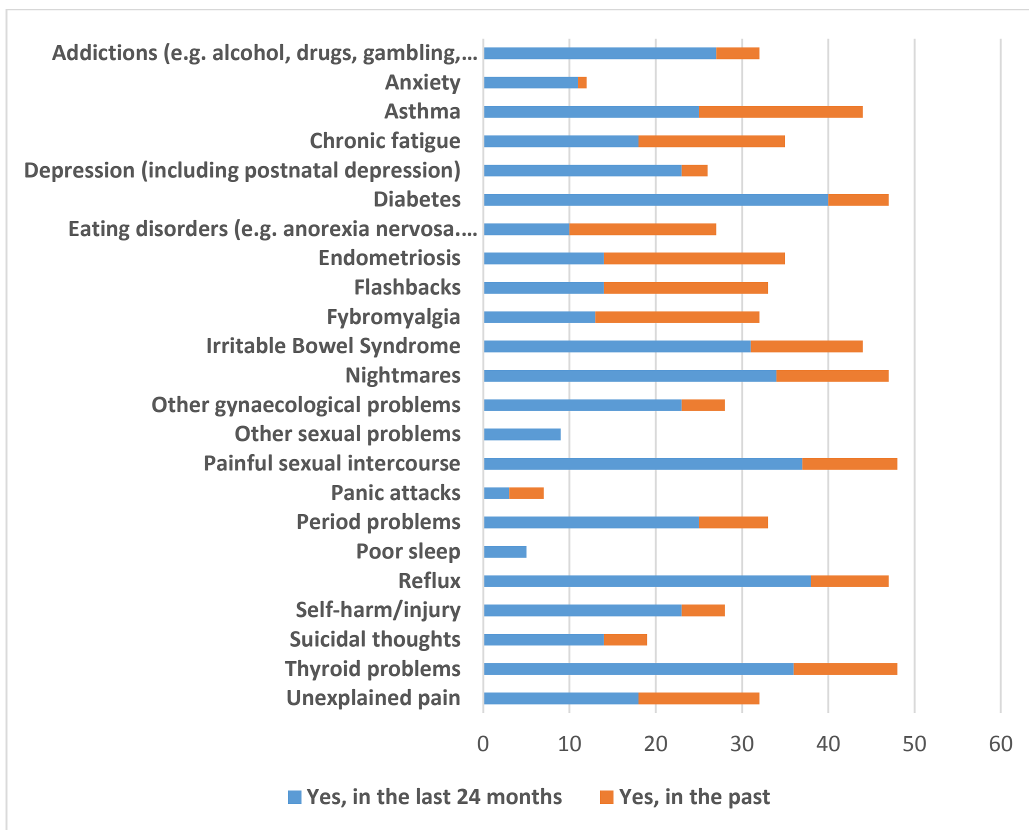
The work of Catherine Itzen (2006) amongst others has identified a number of health issues that commonly affect survivors of childhood sexual abuse. We used her work and previous work from a former Trustee of CIS'ters to identify issues about which to ask respondents for this survey. Their responses are shown in table 2. All 49 respondents answered this question, although not all included a response against every condition. Therefore rows do not always add up to 49.

**Table 2 Survivors' Health Issues**

| Evidence suggests that it is common for survivors to experience a number of health issues. Have you experienced any of the following? (Please tick all that apply) | | | | |
|---|---|---|---|---|
| Answer Options | Yes, in the last 24 months | Yes, in the past | Never | Not sure |
| Addictions (e.g. alcohol, drugs, gambling, shopping or other) | 18 (42%) | 14 (33%) | 7 (16%) | 4 (9%) |
| Anxiety | 36 (75%) | 12 (25%) | 0 | 0 |
| Asthma | 14 (34%) | 5 (12%) | 19 (46%) | 3 (7%) |
| Chronic fatigue | 23 (56%) | 5 (12%) | 11 (27%) | 2 (5%) |
| Depression (including postnatal depression) | 38 (79%) | 9 (19%) | 0 | 1 (2%) |
| Diabetes | 5 (13%) | 0 | 33 (85%) | 1 (3%) |
| Eating disorders (e.g. anorexia nervosa. bulimia, obesity or other) | 25 (57%) | 8 (18%) | 9 (20%) | 2 (5%) |
| Endometriosis | 3 (8%) | 4 (10%) | 24 (60%) | 9 (23%) |
| Flashbacks | 37 (76%) | 11 (22%) | 1 (2%) | 0 |
| Fybromyalgia | 9 (24%) | 0 | 25 (68%) | 3 (8%) |
| Irritable Bowel Syndrome | 23 (52%) | 5 (11%) | 14 (32%) | 2 (5%) |
| Nightmares | 34 (69%) | 13 (27%) | 1 (2%) | 1 (2%) |
| Panic attacks | 31 (65%) | 13 (27%) | 4 (8%) | 0 |
| Painful sexual intercourse | 13 (31%) | 19 (27%) | 9 (21%) | 1 (2%) |
| Other sexual problems | 14 (34%) | 19 (46%) | 7 (17%) | 1 (2%) |
| Period problems | 14 (32%) | 21 (48%) | 7 (16%) | 2 (5%) |
| Other gynaecological problems | 10 (22%) | 17 (38%) | 14 (31%) | 4 (9%) |
| Poor sleep | 40 (82%) | 7 (14%) | 2 (4%) | 0 |
| Reflux | 23 (59%) | 3 (8%) | 11 (28%) | 2 (5%) |
| Self-harm/injury | 18 (43%) | 17 (40%) | 7 (17%) | 0 |
| Suicidal thoughts | 25 (54%) | 19 (41%) | 2 (4%) | 0 |
| Thyroid problems | 11 (29%) | 1 (2.7%) | 23 (60%) | 3 (8%) |
| Unexplained pain | 27 (63%) | 5 (12%) | 8 (19%) | 3 (7%) |

The extent of the morbidity faced by these survivors is presented graphically in Figure 4. All had experienced anxiety at some stage and 98% have had both depression and flashbacks. Ninety six percent acknowledge problems with poor sleep and nightmares; 95% of the women have had suicidal thoughts and 92% have had panic attacks. Eighty three percent admit to self-harm and a further 75% have had addictions and eating disorders. Seventy five percent of the women have experienced unexplained pain. Sites for unexplained pain were described all over the body but most commonly in the head, neck, back, shoulders, stomach and pelvis.

**Figure 4 Survivors' morbidity**




Women have not always accessed health care professionals for advice about these issues. Table 3 shows how they rated the care they received when they did. For clarity the table omits the women for whom this was not applicable (i.e. they had not experienced the problem), but this means that the numbers do not add up to 100%.

**Table 3 Satisfaction with care for health issues**

| If you have accessed health professionals for any of these conditions in the last 24 months, how would you rate the care you received? | | | | |
|---|---|---|---|---|
| **Answer Options** | **Good** | **Satisfactory** | **Poor** | **I did not see a health professional** |
| **Addictions (e.g. alcohol, drugs, gambling, shopping or other)** | 4 (12%) | 0 | 2 (6%) | 18 (53%) |
| **Anxiety** | 15 (35%) | 13 (30%) | 10 (23%) | 3 (7%) |
| **Asthma** | 8 (27%) | 6 (20%) | 1 (3%0 | 2 (7%) |
| **Chronic fatigue** | 5 (15%) | 5 (15%) | 6 (18%) | 7 (21%) |
| **Depression (including postnatal depression)** | 16 (36%) | 13 (30%) | 10 (23%) | 2 (5%) |
| **Diabetes** | 2 (7%) | 3 (11%) | 0 | 3 (11%) |
| **Eating disorders (e.g. Anorexia nervosa. bulimia, obesity or other)** | 2 (6%) | 4 (12%) | 9 (27%) | 13 (39%) |
| **Endometriosis** | 3 (12%) | 0 | 1 (4%) | 3 (12%) |
| **Flashbacks** | 7 (18%) | 7 (18%) | 8 (21%) | 16 (41%) |
| **Fybromyalgia** | 2 (7%) | 2 (7%) | 4 (14%) | 3 (11%) |
| **Irritable Bowel Syndrome** | 6 (17%) | 5 (14%) | 7 (20%) | 7 (20%) |
| **Nightmares** | 8 (19%) | 3 (7%) | 9 (21%) | 21 (50%) |
| **Panic attacks** | 9 (22%) | 9 (22%) | 9 (22%) | 13 (32%) |
| **Painful sexual intercourse** | 1 (3%) | 3 (9%) | 4 (12%) | 17 (50%) |
| **Other sexual problems** | 1 (3%) | 3 (9%) | 4 (11%) | 18 (51%) |
| **Period problems** | 7 (20%) | 5 (14%) | 5 (14%) | 6 (17%) |
| **Other gynaecological problems** | 6 (19%) | 5 (16%) | 3 (9%) | 3 (9%) |
| **Poor sleep** | 12 (29%) | 8 (20%) | 9 (22%) | 11 (27%) |
| **Reflux** | 10 (31%) | 4 (13%) | 3 (9%) | 7 (22%) |
| **Self-harm/injury** | 7 (21%) | 6 (18%) | 3 (9%) | 11 (32%) |
| **Suicidal thoughts** | 5 (13%) | 11 (28%) | 7 (18%) | 10 (26%) |
| **Thyroid problems** | 2 (8%) | 5 (19%) | 2 (8%) | 4 (15%) |
| **Unexplained pain** | 1 (3%) | 7 (19%) | 10 (27%) | 8 (22%) |

GPs were key in the experiences of respondents; several of whom commented on how caring their GP had been. One specifically recognised how good her GP is in relation to her mental health. Another was grateful for the response she received when she first became aware of her abuse.

*'I was lucky enough to have a kind, mature lady GP who prescribed CBT sessions. I could NOT have disclosed sexual abuse to her younger arrogant macho male partner!'*

Others were less complimentary. One suggested her GP had *'not a clue'.* Another, usually well supported by her GP had a less positive experience when she was struggling at a time she was having to see her abuser again following a death in the family:

*'I went to the surgery to discuss my emotional wellbeing and a need for anti-depressants however the GP I saw was not my usual and he was overly interested in the specifics of the abuse which unsettled me. Mid asking me questions about penetrative abuse the doctor switched to talking about my weight and was extremely pushy about discussing my eating habits. I was tearful from the previous part of the conversation and it all felt very strange. I made a complaint subsequently and suggested that the doctor needed to go through some training for how to support survivors but the complaint seemed to be being brushed off and my concerns were not acknowledged as being serious.'*

There are two issues here: the insensitivity of the GP in the first place and the lack of acknowledgement of the complaint. This relates to the need to be heard mentioned earlier and is highlighted in other comments:

*'I feel like I am viewed as a medical problem to be managed and not as a person to be listened to.'*

Perceived lack of compassion in the mental health services was again an issue. Three of the women who made comments had resorted to private treatment in which they felt their needs were better addressed.

Sixteen of the women (33%) were prescribed drugs by a psychiatrist. Fifteen of them answered the question about when these were last reviewed. Two women had had their medication reviewed in the previous month and five in the previous six months (although one had requested this). A further five had either commenced medication or been reviewed in the previous year. Of the remaining three, one did not know, one was reviewed 4-5 years ago and the third just said 'too long!' Several of the women had accessed 'Talking therapies'. Some had been referred to the service, others had asked for it. Most women who had accessed a Talking therapy found it helpful (see Table 4). These therapies were mostly accessed through the NHS, although eighteen women had used private services and one had been given access through work.

**Table 4 Use of 'Talking therapies'**

| Some survivors find services such as counselling and psychotherapy helpful. Have you ever accessed any of the following? (Please tick all that apply) | | | | | | |
|---|---|---|---|---|---|---|
| Answer Options | **I have not used this service** | **I was referred to this service** | **I asked for this service** | **Helped** | **Did not help** | **Not sure** |
| **Cognitive Behavioural Therapy (CBT)** | 2 (36%) | 12 (36%) | 3 (9%) | 10 (30%) | 8 (24%) | 2 (6%) |
| **Dialectical Behaviour Therapy** | 20 (67%) | 6 (20%) | 0 | 5 (17%) | 1 (3%) | 3 (10%) |
| **Mindfulness** | 18 (53%) | 7 (21%) | 4 (12%) | 8 (24%) | 3 (9%) | 2 (6%) |
| **Mental Health Group Therapy** | 18 (56%) | 10 (31%) | 0 | 6 (19%) | 5 (16%) | 2 (6%) |
| **One-to-one at local rape crisis or specialist organisation** | 8 (23%) | 6 (17%) | 13 (37%) | 14 (40%) | 4 (11%) | 1 (3%) |
| **Other** | 7 (19%) | 8 (22%) | 14 (38%) | 23 (62%) | 5 (14%) | 0 |

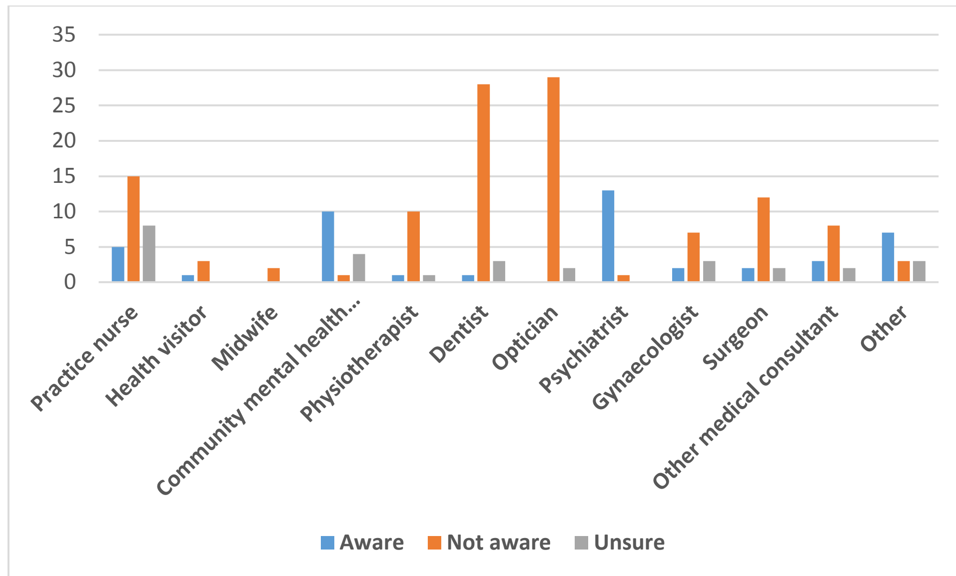
## 3.5 DISCLOSURE

Thirty two women (67%) had disclosed their childhood sexual abuse to their GPs and 16 (33%) had not. Two indicated that they had not disclosed because they had not felt the need to and others were not sure how to broach the subject. The related issues of trust and continuity were mentioned by several of the women as factors needed to make disclosure possible. Women indicated that they would be more inclined to tell the GP if they knew who they were going to see and had been able to establish a relationship with them. Others had been put off by reactions to previous encounters:

*'When I did disclose many years ago about my father and I was concerned about his Granddaughter he* [the doctor] *said he is in is 70's and therefore not a threat. I would not have trusted him. Therefore I would never disclose again.'*

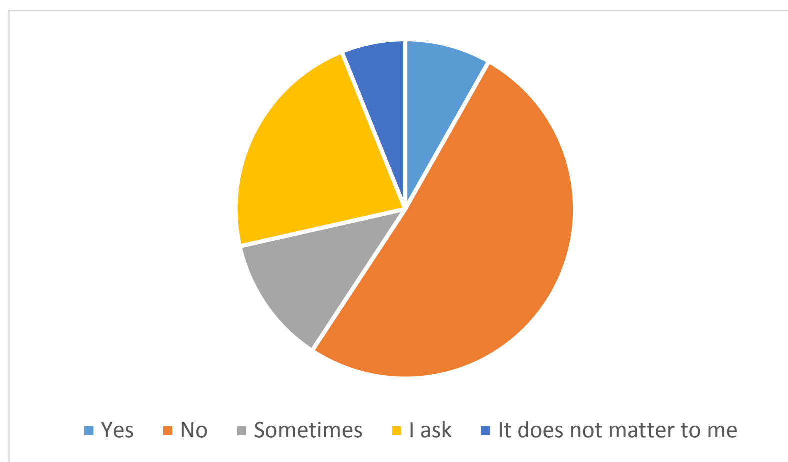
With the exception of psychiatrists and community mental health nurses, the majority of women did not disclose to healthcare professionals other than their GP, as shown in Figure 5. Thirty four women indicated what might make it possible to disclose. Six of them either did not want to tell or feel the need to and a further eight said they would if it was relevant or on a 'need to know' basis. Privacy emerged as an issue as did time in which to address the subject. Six women would have liked to have been asked – perhaps via a questionnaire on registration or to have had staff alerted to their history by a discrete sticker on their medical notes. Others indicated that there was something in their past that might makes aspects of treatment difficult but did not name abuse.

**Figure 5 If you have seen any of these health professionals, are they aware you experienced sexual abuse as a child?**




Having female practitioners was important for some of the women and one had specifically written requesting to be moved to a female GP but she was unsure if anyone knew the reason why. As shown in Figure 6, more than half of the respondents were not routinely offered choice about the gender of the health professionals they saw. Only 8% were routinely offered a choice. However, 22% of women said they ask and a further 6% said it did not matter to them.

**Figure 6 Are you routinely offered a choice in gender of the health professionals you are due to see?**



## 3.6 Caring for survivors

Some regular themes have emerged in this survey from which recommendations for practice can be made. Survivors of childhood sexual abuse may face multiple issues with both physical and mental health and are therefore regular users of the health service. Any encounter with a health care professional can leave them feeling vulnerable yet the majority do not disclose. Disclosure requires trust which can be facilitated by continuity but also by privacy, patience and time. Disclosure can be very difficult and survivors are wary of the response they might get if they do find the courage to speak out. One respondent said:

*'If I knew I would be understood and not judged by my abuse then maybe I would say but I'm scared to say anything as I could end up by not having support and feeling worse than I do already'*

Survivors will not necessarily know how they will react from day to day, so it is really important to listen to them and to treat them as individuals. The following comments from respondents provide a powerful reminder of that:

*'See me as a person, not a diagnosis. Try to show empathy. As a survivor I will close right down if I sense insincerity or lack of empathy. I will respond to kindness however.'*

*'It's hard to share, even if it would be in our own best interests to do so. If someone is brave enough to disclose, please accord them dignity and respect and don't assume that you know how they will be affected as a result. We are all unique, survivors or not.'*

*'All the so called professionals have no idea. They judge you on - - - you have a problem with alcohol - - - and you are labelled for the rest of your life. I never chose this. It's a life sentence.'*

Not all survivors will have difficulty being treated by a male, but a significant number will. It is therefore important, if at all feasible to offer women the option of being seen by a female member of staff. It is also important to remember to respect people's privacy. It is not always possible for people to speak out – especially if they are experiencing triggers or flashbacks. Respecting personal space is particularly important when dealing with survivors:

*'One consultant I saw made me feel uncomfortable because when talking to me he sat very close in front of me with my legs between his.'*

# 4 RECOMMENDATIONS

1. Primary healthcare workers should be provided with basic awareness in core issues related to the emotional and physical health impact resulting from experiencing rape/ sexual abuse during childhood.
2. Healthcare professionals within midwifery and allied professions should be provided with basic awareness in core issues related to not only the emotional impact, but also physical health issues that might arise following a history of childhood sexual abuse.
3. As many survivors do not disclose to healthcare professionals it is important to be aware that any woman (or man for that matter) may be a survivor and may therefore find encounters with healthcare practitioners difficult.
4. Focus should be on healthcare professionals creating a disclosure-friendly service, which does not necessarily require the patient/client to make such a disclosure.
5. It is important not to assume that denial of a history of childhood sexual abuse definitely means there is not one. Healthcare practitioners must remain alert to cues from patients.
6. Continuity of care is really helpful.
7. If possible, offer women a choice of gender of the healthcare professional they see – or at least warn them if it will only be possible to see a man.
8. A non-judgemental attitude is really important.
9. Kindness goes a long way to making people feel at ease

# 5 CONCLUSION

This survey of 49 members of CIS'ters has provided a snapshot of the health issues and care needs of survivors of childhood sexual abuse. There are many examples of excellent care and compassionate practitioners but there are also accounts of failure to treat people as individuals and to see a label or diagnosis rather than a person with needs behind it. There is a clear plea from the women who responded to the survey for healthcare professionals to listen so that they can understand their health needs and work together to address them.

# 6 REFERENCES

Itzin, C. (2006) *Tackling the health and mental health effects of domestic and sexual violence and abuse.* London: Crown copyright

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