FERTILITY PATIENTS' EXPERIENCES OF CROSS-BORDER REPRODUCTIVE HEALTH CARE

Background

This on-line survey was commissioned by Assisted Human Reproduction Canada on behalf of the planning committee of the "First International Forum on Cross-Border Reproductive Care: Quality and Safety" in order to gather information directly from people who have either experienced reproductive health care in a country other than their own or have considered doing so. The survey was supported by three patient organisations: ACCESS (Australia), and Infertility Awareness Association of Canada (IAAC) and Infertility Network (Canada). The questionnaire was based on one used in a survey of "fertility tourism" undertaken by Infertility Network UK (I N UK), the patient organisation for the UK, between 20 February and 20 June 2008, and was developed in conjunction with the three partner organisations and Assisted Human Reproduction Canada. The survey was "live" for three months from 1 July until 30 September 2008 and was accessed via the websites of ACCESS, IAAC and Infertility Network.

This report provides a summary of the survey results which, by agreement with I N UK, are compared with the results of the I N UK "Fertility Tourism" survey.

Results

One-hundred-and-thirty-one submissions were made. Thirty-six of these were not usable because insufficient information was supplied to enable analysis to be undertaken or participants made it clear that they were neither actual nor intending users of cross border reproductive health services. Of the 95 usable responses, 28 were from individuals who indicated that they had actually received reproductive services in another country.

For reasons outlined below, the data presented here should be viewed, not as "hard science" but rather, interpreted as indicative of potential issues and trends.

Geographical location of participants

As would be expected, given the geographical locations of the support organisations, most participants indicating their country of origin were from Canada (55; 60%), or Australia (22; 24%) – although reflecting the international context of internet use, 14 (15%) participants indicated that they were from other countries (specifying the USA, Israel, the UK and Greece).

Gender of participants

As might also be expected, the vast majority of participants indicating their gender were female (86; 91%) vs male (9; 9%).

Recipients vs donors

Although the survey was open to donors as well as those undergoing or seeking services, only two participants were evidently **not** a recipient – a semen donor who reported having received enquiries from potential offspring living in different countries and a woman planning to be a surrogate for a family member.

Age of participants

Ninety-one participants disclosed their age, as follows:

Age	**No (%)**
Under 30 years	6 (6%)
30-39 years	47 (52%)
40-49 years	35 (38%)
Over 50 years	3 (3%)

Treatment in own country before seeking or considering treatment in another country

A significant majority of participants (76), 86% of those answering this question, indicated that they had received fertility treatment in their own country before seeking, or considering seeking, treatment in another country. The length of time in treatment in the home country before contemplating treatment elsewhere ranged from 2 months to 8 years:

Length of time before seeking or considering treatment in another country	**No (%)**
< 1 year	8 (13%)
1 year < 2 years	10 (16%)
2 years < 3 years	10 (16%)
3 years < 4 years	11 (17%)
4 years < 5 years	11 (17%)
>5 years	14 (22%)

A number of participants provided answers to this question (e.g. “a few years”, “after 2 failed IVFs”) that could not be categorised.

Finding out about treatment in other countries

The survey asked how participants had found out about treatment in a country other than their own[1]. Sixty-one (64%) cited the internet, followed by a patient support group (20; 21%); media sources other than the internet (19; 20%); another patient (14; 15%); the clinic treating the individual in their own country (13; 14%); and a friend or family member (4; 4%).

Countries in which participants sought treatment

Of the 69 participants who cited at least one country in which they had received or planned to seek treatment, 37 (54%) mentioned the United States, the single most

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[1] Participants were invited to identify all sources of information they had used, so each participant was able to indicate more than one source.

frequently-mentioned “destination”. However, a wide range of specific countries – 24 in total - was listed (Argentina, Australia, Bangladesh, Barbados, Belgium, Canada, Cyprus, the Czech Republic, Denmark, France, Greece, India, Israel, Italy, Mexico, the Netherlands, Russia, South Africa, Spain, Thailand, Turkey, Ukraine and the United Kingdom) together with general regions in Africa, Asia, Eastern Europe and South America (without specifying a named country). While the majority of participants specifying a country named one country only, a small number listed multiple potential destinations. For example one Australian participant cited “Western Australia, Tasmania, Victoria, and Sydney[2]”; one Canadian participant cited “USA, Mexico, UK”; one US participant replied “I received treatment in Czech Republic. I am considering going back there, or possibly Argentina or South Africa, depending on how things work out w/my fertility clinic here in the USA”. Another participant from the US cited “Ukraine, Countries in Africa, Eastern Europe, Canada.”

Treatments sought

Of the 28 participants who reported having had treatment in another country, egg donation (16; 57%) was the most frequently-mentioned treatment type. Other reported treatments were: IVF (7; 25%); ICSI (5; 19%); sperm donation (5; 19%) IUI (3; 11%); embryo donation (2; 7%), tubal surgery (2; 7%) and surrogacy (1; 4%). Some participants mentioned having received multiple services e.g. egg donation/IVF; IVF/ICSI[3].

Factors taken into account in seeking treatment in another country

Participants who had received treatment in another country identified the following factors they had taken into account when doing so[4]:

Factors taken into account	**No (%)**
Availability of donor eggs/sperm	21 (75%)
Success rates	18 (64%)
Short waiting times	17 (61%)
Cost of treatment	15 (54%)
Unavailability of services in home country	14 (50%)
Positive reports from other patients who have received treatment in another country	8 (29%)
Recommendation from clinic own country	3 (11%)
Opportunity to have more embryos replaced	2 (7%)

Making arrangements regarding treatment in another country

Twenty-five participants answered this question. Nineteen (76%) had made their own arrangements; five (20%) reported that arrangements had been made by an individual or agency other than a clinic in own country, and none reported that arrangements had

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[2] In Australia, assisted human reproduction services are regulated at state level, resulting in significant inter-state variations in service provision and regulation. These differences are likely to encourage inter-state travel within Australia to access desired services.

[3] Participants were invited to identify all treatments hay had received, so each participant was able to indicate more than one.

[4] Participants were invited to identify all factors relating to their particular circumstances, so each participant was able to indicate more than one factor they had taken into account.

been made by their clinic in their home country. One participant (4%) reported that the arrangements in their case combined these factors.

Conception as a result of the treatment received in another country

Of the 25 participants who replied to this question, fourteen (56%) indicated that their treatment had been successful and eleven (44%) reported that it had not been successful.

Positive aspects of treatment in another country

Most participants who indicated that they had received treatment in another country responded to this question (25/28). The key positive aspects of treatment cited by these participants were[5]:

Positive aspects of treatment in another country	**No (%)**
Availability of donor eggs/sperm	18 (72%)
Short waiting list	15 (60%)
Cost	12 (48%)
Higher success rates	12 (48%)
Facilities at clinic	12 (48%)
Attitudes of staff at clinic	12 (48%)
Atmosphere at clinic	10 (40%)
Easier to keep treatment a secret from others	8 (32%)
Ability to take a holiday at the same time	6 (24%)
Ability to put back more embryos	3 (12%)

Negative aspects of treatment in another country

Somewhat fewer than those reporting positive aspects, reported negative aspects of treatment in another country (23/28), as follows[6]:

Negative aspects of treatment in another country	**No (%)**
Difficulty finding a clinic for bloods and scans in own country	8 (35%)
Travel difficulties	8 (35%)
Cost higher than expected	8 (35%)
Language/communication problems	5 (22%)
Lack of regulation	3 (13%)
Communication problems between referring clinic/agency and clinic where treatment provided	3 (13%)
Complications with treatment	2 (9%)

Counselling

Of the 25 responses to questions about counselling, two were excluded from analysis because of contradictory responses (where the participant had claimed both that they

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[5] Participants were invited to identify all factors relating to their particular circumstances, so each participant was able to indicate more than one positive aspect of their experience.

[6] Participants were invited to identify all factors relating to their particular circumstances, so each participant was able to indicate more than one negative aspect of their experience.

had **not** been offered counselling **and** that they had taken up the offer). Slightly more than half (12) of the eligible responses indicated that counselling had been offered. Of these, nine reported that the clinic had its own counsellor and three reported an arrangement with a counsellor in their home country.

Nine participants had accepted counselling. Of these, seven indicated satisfaction with the counselling offered (one was not satisfied and one did not indicate whether she was satisfied or not). In only two instances did participants report that the counsellor had discussed health and safety implications (both for the recipient and for any child) of having treatment in a country other than her home country, and three said that this had not been discussed in counselling.

Of those participants who had not been offered counselling (11), only three thought it would have been useful. One gave no opinion and seven considered that counselling would not have been useful. As might be expected, none of the participants who had been offered counselling but did not take it up thought that it would have been useful

Planning to have further fertility treatment in another country

Ten participants who had already received treatment in another country were considering doing so again. Egg donation (9) was indicated as the most likely form of treatment; other treatments mentioned were IVF (3); ICSI (3); sperm donation (2); surrogacy (2) and embryo donation. Of those not planning further fertility treatment in another country, the success of previous treatment (7) was given as the most common reason for this, followed by cost (3); time (2) and unsuccessful treatment (2). One participant referred to the quest for further treatment "detracting from quality time with current newborns" and three participants recounted particularly unsatisfactory experiences in the treatment they had already received:

"The treatment made me extremely ill"

"We felt trapped and used by a very unethical team of otherwise highly respected doctors. We were given false hopes, wrong success rates, the quality of the work done was very low (much lower than what we had previously experienced at home), the price sky rocketed contrary to initial arrangements etc, etc, etc... Somebody should stop these ruthless people".

"We were cheated, we're not going through this again..."

Nature of planned treatment where treatment in another country not already undertaken

Fifty-nine participants who had not already received treatment in another country specified the treatment in which they were interested. Some indicated interest in more than one treatment e.g. IVF/ICSI; IVF/egg donation[7].

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[7] Participants were invited to identify all treatments they were considering, so each participant was able to indicate more than one.

Nature of planned treatment in another country	**No (%)**
IVF	39 (66%)
ICSI	18 (31%)
Egg donation	18 (31%)
Surrogacy	10 (17%)
IUI	7 (12%)
Ovulation induction	6 (10%)
Sperm donation	6 (10%)
Embryo donation	4 (7%)

Factors that should be taken into account by potential users of services in another country

This question was open to all survey participants, and 78 responded, as follows[8]:

Factors that should be taken into account by potential users of services in Another country	**No (%)**
Cost of treatment	63 (81%)
Success rates	61 (78%)
Short waiting times	49 (63%)
Positive reports from other patients who have been to this clinic	47 (60%)
Availability of donor eggs/sperm	41 (53%)
Unavailability of services in home country	39 (50%)
Recommendation from clinic in own country	31 (40%)
Implications for child of having treatment in a country other than home country	14 (18%)
Opportunity to have more embryos replaced	10 (13%)

Further comments

Thirty one participants added further comments. For the most part, these elaborated on issues covered elsewhere in the survey rather than introducing anything new. These could be broadly grouped as follows (NB these total more than 31 since some responses referred to more than a single issue):

Themes of "further comments"	**No (%)**
Concerns about quality of service, costs/restrictions on services in their home country	11
Financial aspects of treatment in another country:	8
Better services in another country	7
Giving more information about their personal circumstances that had resulted in their quest for treatment in another country	4
Need for information	2
Concerns about professional and safe services in other countries	3
Need for continuity of care involving clinics in the destination and home countries	1
Stress of undertaking cross-border reproductive services	1
Transfer of medical history between clinics	1

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[8] Participants were invited to identify all factors they considered should be taken into account, so each participant was able to suggest more than one factor.

Discussion

It is important, first, to note the limitations of this study.

A relatively small number of individuals participated in the survey and, of the responses submitted, just over a quarter had to be excluded from analysis. This was primarily the result of incomplete returns, where individuals had either included no information at all or provided no information beyond their country of origin, gender and age. It is not at all clear how or why this should have occurred. The survey allowed for individuals to "drop out" at any point before completion, while submission of the survey required a positive action on the part of the individual. Incomplete returns, therefore, could not have been submitted "accidentally". Following further evaluation, two more returns were excluded since in each case the respondent declared her ineligibility to participate by making an explicit statement that she had neither undertaken reproductive treatment in another country, nor intended to do so.

The methodology also suffers from well-known limitations. All participants in this study were self-selected and since data were self-reported anonymously it is not possible to guarantee the accuracy of the information provided. Participants may, to put it simply, lie in respect of their eligibility to participate in the first place and may also be prone to respond in socially desirable ways or to misrepresent their "real" views in relation to the information they provide. Furthermore, the survey is open to multiple responses from the same individual, although since each completed return was inspected visually by the principal investigator, the risk of duplicate responses was avoided – this check revealing no attempt to submit multiple duplicates. Nevertheless, it would still be possible for the same individual to post multiple responses containing **different** information. The only real safeguard against this having occurred to any great extent here – and in respect of the more general issue of participant integrity – is why anyone would take the trouble go to such lengths to falsify information. However, it needs to be borne in mind that these problems are not unique to this form of data-gathering, and no social science research can be totally immune from shortcomings and potential abuses.

On reflection, it was also evident that questions concerning donor anonymity in the survey (raised in respect of "Factors taken into account in seeking treatment in another country", "Positive aspects of treatment in another country" and "Factors that should be taken into account by potential users of services in another country") were ambiguous. It was apparent, for example, that the ability to travel to another country either to use gametes provided by an anonymous donor or to use gametes provided by an identifiable donor was valued by some participants. However the question was interpreted, it did not seem to figure predominantly in participants' responses. Nevertheless, issues relating to donor anonymity have not been included in the analysis.

Who seeks reproductive services in another country

Intuition alone would suggest that seeking reproductive services away from home would neither be an individual's first thought nor something to be undertaken lightly. Insofar as this survey was able to test out these assumptions, it is evident that the vast majority of participants (94%) were aged over 30, 86% had received treatment in their own country before seeking, or considering seeking, treatment in another country and more than half of participants (56%) had had treatment in their home country for at least three years before considering going elsewhere.

Finding out about treatment in other countries

It is evident that ostensibly unregulated sources (the Internet and other media) represent the main source of information accessed by patients and prospective patients regarding treatments in other countries; other reported sources of information include patient support groups, other patients and the clinic treating the individual in their own country. Given their own experiences, it is interesting to compare these with the relative importance participants gave to these when asked to indicate factors that should be taken into account by potential users of services in another country (see below).

Countries in which participants were considering treatment

Geographical contingency clearly plays some part in determining destinations for reproductive services; while, apart from clinics in other regions of the participant's home country (i.e. Australia and Canada), the USA and Mexico were the most frequently mentioned destinations in this survey, the "top" destination in the I N UK survey was Spain, mentioned three times as frequently as any other destination country. As indicated above, participants in this study identified as destinations 24 individual countries and four general regions in Africa, Asia, Eastern Europe and South America. When combined with responses to the I N UK survey, this total is taken to 29 individual countries and five general regions (the above regions plus "Europe"). While some countries have established reputations as destination countries, such as Spain, the USA and some eastern European and south Asian countries, other countries mentioned by participants in this study are less commonly perceived as likely locations for reproductive services (e.g. Bangladesh, China, Egypt, Turkey). While the survey did not explore detailed reasoning behind individual choices, apart from the more commonly-articulated reasons for cross-border travel for reproductive services, the characteristics of both Australia and Canada as "migrant nations" should not be overlooked. In both countries, many current citizens retain family ties in their country of origin which may increase the possibility of the country of origin being perceived as a place for further treatment, because of familiarity, connections, and access to donor gametes of their own ethnic/racial background. This is an area that should be explored in more depth in future studies.

Services in which participants were interested

Egg donation - at 57% of all responses - was the most frequently mentioned service sought by participants who had received treatment in another country. This was also the most frequently mentioned service (at 41%) sought by participants in the I N UK survey. Somewhat fewer participants in both surveys indicated interest in other third party procedures (responses for this survey are provided first): sperm donation (19% vs 7%); embryo donation (7% vs 1%); surrogacy (4% vs 3%). As regards procedures not involving a donor or surrogate, 25% of participants in this study, compared to 13% of I N UK participants were interested in IVF; 19% vs 25% in ICSI, and 11% vs

4% in IUI. Two participants in this study (7%), but none in the I N UK study, said that they had travelled to another country for tubal surgery.

Among those considering, but not having received, treatment in another country, interest in specific services was somewhat different. Thirty one per cent were interested in egg donation; 17% in surrogacy, 10% in sperm donation and 7 % in embryo donation, while 66% were interested in IVF, 31% in ICSI, 12% in IUI, and 10% in ovulation induction.

Why individuals consider treatment in another country

The “headline” reasons for seeking treatment in another country (identified by over half of all participants) are: availability of donor eggs/sperm (75%); success rates (64%); short waiting times (61%); cost of treatment (54%), and unavailability of services in home country (50%). There is some correlation with the “top five” reasons given by participants in the I N UK “fertility tourism” survey (similarly reported by more than half of all participants): short waiting times (70.5%); cost of treatment (69.5%); success rates (61%); availability of donor eggs/sperm (53.8%), and positive reports from other patients (51%). “Unavailability of services in home country” was not a specified response in the I N UK survey, and was not freely reported by many participants in that study, although one respondent in the present study graphically described what she perceived as the limitations in the services available in her home country:

“Publicly available, VERIFIED success rates for each clinic are absolutely critical. We were devastated with the service we received at clinics in [home country]. [Clinics in home country] are not required to register their success rates. Every time we saw a doctor we received a different version of their success rates (even from the same doctor!) We were told their success rate was upwards of 70% for our procedure. Later, we were told 'that was for multiple procedures'. Later we found out the embryologists actually used abnormal sperm! There is, of course, a lot of money to be made and patients are being exploited. In hind sight, we wish we had gone to the US where clinic rates are available online. We asked for a 5 day blast transfer only to be told that 3 day transfers are better. We had read reports to the contrary. We feel our doctor in [home country] just lied because they don't have the expertise here. So much heartbreak and frustration, we have had to move on. I hope your survey helps infertility patients worldwide”.

Two other observations to be made about these responses are: first, that few participants considered travelling to another country specifically to avoid domestic limitations on the number of embryos that may be replaced, although this was mentioned by some participants (7% - and 23.3% in the I N UK survey)[9]; second, that in both surveys, “positive reports from other patients” was more frequently mentioned than “recommendation from clinic treating you in own country” – 29% vs 11% in this study and 51% vs 23.3% in the I N UK survey.

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[9] Currently, there are no limits on the number of embryos that may be transferred in a single treatment cycle in Canada, so there would be no incentive for Canadians to travel to another country for this reason alone.

Making arrangements regarding treatment in another country

The majority of participants (76%) made their own arrangements – a result reflected also in the I N UK survey, where 88% of participants indicated so doing. In the I N UK survey, 10% of participants followed up a "recommendation" from a UK clinic and 4% reported that their treatment had been arranged by a UK clinic. Neither of these alternatives was mentioned by participants in this study, although 20% indicated the involvement of a third party other than their clinic in their home country in making these arrangements. What emerges from these responses, taken together with the major sources of information about services in other countries (the internet and other media) and the lack of involvement of domestic clinics in making any arrangements (see below), is that to a large extent, those contemplating reproductive services "away from home" are largely reliant on their own resources.

Experiences of treatment in another country

Given that the objective of any form of reproductive services is the conception of a child, the fact that over half of the participants who had experience of services in another country came away with a child provides evidence of some measure of success. Participants were also asked about positive and negative aspects about their treatment in other countries. Judged exclusively in terms of frequency of responses, positive experiences (117) outnumbered negative experiences (43) by almost three to one. The I N UK survey asked participants to indicate whether they were "happy" with the service they received and - if not – what problems they had encountered. Only those indicting that they were not "happy" were then invited to identify the problems they had encountered. The present survey, on the other hand, anticipated that the same individual might have had both positive and negative experiences of their treatment - as indeed appeared to be the case. Among the most frequently-mentioned positives were instrumental elements such as: availability of donor eggs/sperm (72%); short waiting list (60%); cost (48%); higher success rates (48%). These were also the most frequently-mentioned positives (although in a slightly different order) by participants in the I N UK survey: short waiting lists (78%); cost (66%); availability of donor eggs/sperm (60%); higher success rates (41%). A significant minority of participants valued clinic facilities, staff attitudes and the atmosphere at the clinic, and in broadly similar proportions to participants in the I N UK survey (48% vs 36%; 48% vs 38%; 40% vs 40% respectively). While some participants (24%) agreed that treatment in another country provided the opportunity to "take a holiday at the same time" (thus providing modest support for the now largely abandoned concept of "fertility tourism", there was little evidence of participants taking the opportunity to transfer a higher number of embryos (12%), although as noted above, there would be no incentive for Canadians to seek treatment in another country for this reason only.

As indicated above, there were more positive that negative comments. Illustrative positive comments included:

"The quality of care received in the clinic that I went to far surpassed what I received in the UK which was like being on a conveyer belt. The added bonus of being less expensive and no waiting times adds to the incentive. it is a real shame that UK residents receive a better service from other countries than they do in the UK".

“In India, my RE did all the ultrasounds herself. at home i never see my RE during my cycle, u/s are done by different docs every time.”

and

“Whereas I unfortunately didn't get pregnant in my overseas attempt, it was a wonderful experience and since the wait times and costs were so much less, and I didn't feel that my medical care overseas was the least bit compromised, I highly recommend it and will probably do it again once I have all of the testing done here to increase my chances the next time”.

As has already been noted above, some negative comments indicated extremely strong reactions. These apart (although not to be ignored, of course), most negative comments were rather more mundane. Interestingly, the most frequently reported problem was difficulty in finding a clinic in the participant’s home country to undertake tests and scans (35%). A similar number reported travel difficulties and higher costs than expected, while language problems were reported by 22%. Relatively few participants (13%) reported concerns about a lack of regulation in the destination country – although this could, of course, be negatively interpreted that participants could be satisfied with the levels of regulation as much as being unconcerned about any absence of regulation. Only one participant reported concerns about “legal/liability issue[s]”, although this was, for them, the “Biggest issue”. It may be that the importance of this was under-estimated in this survey (and also in the I N UK survey) since it was not specifically highlighted as a possible response to this question. In the I N UK survey, three predominant concerns were reported by participants: language and communication (47%); lack of regulation (including problems with having to use an anonymous donor) (37%); higher costs than expected (26%). In contrast to this study, only 16% of I N UK participants reported travel difficulties (perhaps reflecting the comparatively high proportion undertaking relatively short journeys to Spain and other European countries), while only 5% experienced difficulty in finding a home clinic to undertake tests and scans.

Counselling

While most participants who reported having received counselling indicated their satisfaction with it, it is evident that counselling *per se* does not enjoy an especially high regard among those responding to the survey. The majority of those who were not offered counselling did not seem to regard this as an opportunity missed – a view shared by all three participants who declined the offer of counselling. More positive responses were recorded in the I N UK survey where 63% of participants thought counselling might have been helpful, as opposed to 38% who did not think so. Sixty four percent of participants in the I N UK survey were not offered counselling. Of those who were, 28% reported that the clinic had their own counsellor and 7% reported that the overseas clinic had an arrangement with a counsellor in the UK. Half of those offered counselling, did not take up the offer. Of those who did take up counselling, 83% reported that it was satisfactory, and 17% reported that it was unsatisfactory.

A message from this suggests that if counselling wishes to be seen as an important service, it needs to do more to ensure that those seeking reproductive services in another country are aware of its potential relevance and benefits – at least part of which may include convincing other professionals of its value.

Factors to be taken into account by potential users of services in another country

Although all participants in the survey (not simply those who had already had experience of reproductive services in another country) were given the opportunity to respond to this question, there was a reasonable measure of concordance between the factors identified here and those identified by participants as important in regard to their own treatment. Three instrumental factors (cost of treatment, success rates, and short waiting times) also topped the list of those identified here, although availability of donor eggs/sperm was also identified, as was the more general "unavailability of services in home country". Again, the opportunity to have a higher number of embryos transferred assumed a low level of relevance for participants, while no one identified the opportunity to "take a holiday at the same time". Similarly, the implications for any child of being conceived as the result of treatment in a country other than the individual's home country was considered important by only 14 (18%) participants, a low level of response that should warrant further discussion and study. Totally absent from participants' considerations in respect of this question were clinic facilities, staff attitudes or atmosphere at the clinic (this may attest to the impact in such types of survey of pre-set responses on shaping the answers given).

As indicated above, participants who had actually received treatment abroad most frequently reported the internet and other media as providing information about reproductive services in other countries; in comparison, the impact of reports from other patients[10] or of recommendation from the clinic providing services in the home country was more muted. However, both of these sources, 60% and 40% respectively, received a somewhat higher level of endorsement for future users of such services to take into account.

Further comments

For the most part, these reflected on, or provided further comment relating to, issues already covered in the survey. Specific issues worth highlighting here are acknowledgement of the stress involved in utilising services in another country, over and above the existing highly-stressful experience of infertility and treatment, the need for continuity of care arrangements between clinics in the destination and home countries, and the problems of transfer of medical information between clinics in the home and destination countries.

Conclusions

A key factor underlying responses to this survey relates to the need for accessible, accurate and reliable information. This is primarily information about current "best practice", "cutting edge" procedures (especially where procedures promoted as

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[10] Although it is possible that contact with, and information from, other patients in online forums could have been included as internet sources.

"cutting edge" may be little more than experimental and unproven), the availability of services, specific treatments, success rates, and costs. Participants noted their heavy reliance on internet and other media for information, although several mentioned that this could not necessarily be verified in advance and a couple of participants specifically complained that they had been the victims of mis-information.

One potential way forward identified by participants is increased engagement by clinics in the process in the home country, given that all – or virtually all - those seeking treatment in another country have already undertaken treatment with a clinic in their own country. However, if this were to be developed, it is imperative to ensure that any such involvement – and especially recommendations regarding particular treatments and particular clinics in other countries – is legal and consistent with any regulatory requirements within the jurisdiction in which it operates, in accordance with professional codes of practice to which clinic personnel have subscribed, and guided by what is the best service for the patient concerned and not influenced by relationships between the clinics, especially those of a commercial nature. Where a clinic providing treatment becomes aware of a patient's intentions to seek treatment in another country, it should make available advance information to that individual of the support services that it is in a position to provide, including any legal or regulatory constraints on such services. The need for information that is also independent is essential.

Another way forward highlighted is to make more use of feedback from other patients. The survey did not investigate the ways in which feedback from former patients is accessed or used, although this is probably multifactorial and includes a large element of happenstance and serendipity. It is inevitable that the internet will continue to play a large role in dissemination of information and the best hope of improvement lies in making more sophisticated, systematic and effective use of this. The extent to which governments and/or regulatory agencies should also play a role in promoting patient feedback should also be further debated.

In this regard, lessons from other developed and developing areas of internet use may be usefully drawn. For example, the internet provides effective opportunities for travellers to provide feedback on their experiences of hotels and other travel services (see for example, 'TripAdvisor' - www.tripadvisor.com). More specifically in the health field, websites are being established that enable patients to find out about physicians and other health care professionals and also to post their evaluations of services provided by particular individuals (see for example, 'RateMD.com' - www.ratemds.com; 'Jameda.de' - www.jameda.de; 'Checkthedoc.de' - www.checkthedoc.de). Finally, and responding specifically to the comment made by one participant regarding the transfer of medical history, patients should be able to develop their own 'portable' record medical history and other health information that can be accessed online via a secure URL anywhere in the world, such as is currently being developed by 'Google'.

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We would suggest the following wording on p.8: "... apart from the more commonly rehearsed articulated reasons for cross-border travel..."