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Neasa Connolly
Secretary

Róisín K. O’Sullivan
Editor

Mary Jones-O’Connor
Finance & Marketing Manager

Bebhinn Shane
Editor

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Alex Owens
Deirdre Ryan

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Dr. Amanda McCann
Dr. Cliona McGovern

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Dr. Cliona McGovern
This is a fascinating edition of the UCD Student Medical Journal (UCDsmj) and should be read from cover to cover. It is the product of several years of effort which started with the production of the first edition of the UCDsmj and might have finished there only for the determination of the Journal’s leadership and their supporters. As Director of Educational Development in the School, one of the five goals that I have laid out to be achieved over the next five years is that each student in each programme will have been supported in reaching their individual potential. This edition of the UCDsmj demonstrates the importance of student-led initiatives in achieving that goal. The student contributors have demonstrated that, given the opportunity, they are more than capable of writing articles of great interest to a wide audience and that frequently challenge our knowledge, traditions and values. This form of personal endeavour is of enormous merit and should be multiplied and more systematically incorporated into the student experience at UCD.

There is a theme that permeates this edition of the SMJ that I would like to highlight. Since 2008, the School has partnered with patients through our PACE programme (Patient and Advocate Centred Education and Research). This programme invites patients and patient advocacy organisations to become involved in teaching our students within medical, biomedical and diagnostic imaging programmes. Sometimes, this involves a patient giving a lecture or a seminar. It can also involve groups of patients entering our patient educator programme which ultimately leads to their participation as educators in many of our clinical skills and professionalism learning initiatives. More recently, students have partnered with voluntary organisations in conducting research in domains associated with their cause. I am delighted therefore to note that patients and society feature strongly within this edition, with the role of students and faculty as patient advocates core to many of the articles. The first article highlights the importance of the patient voice in epidermolysis bullosa research. We then meet evidence-based opinion highlighting the need for measures of quality to include patient outcomes in emergency care provision and then articles debating the impact of blood donation policy on society and the continuing food poverty struggle in Ireland. I can’t help thinking that this theme has arisen, in part, because of the School’s unique approach to patient partnership which aims to propagate and harness the innate patient and society centricity of our all our students and staff.

The professional approach of the UCDsmj committee, and their desire to make this Journal sustainable gives great confidence that this is the second of many editions. I note in particular the stellar efforts of Neasa Conneally, Roisin O’Sullivan, Maeve Jones-O’Connor and Bebhinn Shine and their editorial, design and marketing team members. Equally, staff associated with the School have assisted, collaborated, supervised projects and submitted to interviews making this student-led initiative a shining example of what can be achieved through staff-student collaboration. Given the admixture of science, the patient’s voice and the humanities distributed through the edition, it seems fitting to segue to the words of Dr. Anne Merriman. Dr. Merriman, MBE, is a distinguished alumnus of UCD School of Medicine who pioneered the hospice movement in Africa, a continent to which she has devoted the majority of her working life. In an inspiring address to the 2014 Medical Gala Dinner, Dr. Merriman explained to the gathered graduands, that

“patients want to know what’s in your mind and what’s in your heart.”

It appears that we are enabling a generation of medical students who have the capability of rising to Dr. Merriman’s humbling challenge.

Prof. Jason Last
Associate Dean for Programmes & Educational Innovation
UCD School of Medicine & Medical Science
Attitudes to Clinical Research within the Epidermolysis Bullosa (EB) Community

Written by Maeve Jones-O’Connor1, Dr. Amanda McCann1, Avril Kennan2

1 UCD School of Medicine and Medical Science, University College Dublin, Belfield, Dublin 4, Ireland
2 DEBra Ireland, Clanwilliam Terrace, Grand Canal Quay, Dublin 2, Ireland

Keywords: Clinical research, Clinical Trials: Epidermolysis Bullosa; Patient Advocacy; Patient Engagement
BACKGROUND

There has been much investigation of attitudes towards clinical research (CR) in the general population. This research mainly concerns attitudes towards clinical trials in a general sense, i.e. in a non-disease specific way. In the context of rare diseases, the general research is of limited relevance.

OBJECTIVE

The aim of this study was to examine attitudes towards CR and factors involved in clinical trial (CT) participation in epidermolysis bullosa (EB) researchers and patients.

METHODS

This was a two phase, mixed methods study. Semi-structured interviews were used to gather the views of EB clinical researchers (n=11). The results were thematically analysed and inductive analysis was performed. An online survey of patients and carers (n=43) gathered the patient perspective, in relation to factors influencing the decision on whether to partipate in clinical trials and perceptions of clinical research.

RESULTS

The main themes that emerged from the interviews with researchers were: 1) many and varied challenges face EB clinical research 2) there is a degree of polarisation of opinion and experience and 3) community development and collaboration are necessary for progress. There is much variation in attitudes, with some reporting negative experiences of research and low levels of motivation and others, the opposite. Findings of the patient survey highlighted patients’ and families’ motivation to find a cure and relief of local symptoms, but also that there are barriers to participation in the form of fear of risks to health, additional pain and travel issues. Both branches of the study confirmed the importance of a trusting, cooperative relationship between members of the community.

CONCLUSIONS

There are many, varied attitudes towards clinical research in the EB community which are both positive and negative. The cohort of researchers interviewed have high levels of motivation and experience of care and dressing, nutritional support and symptomatic relief of pain and itch. Clinical research (CR) into EB is currently active in a variety of potential treatment domains, including protein, cell, gene and drug therapies. There is no cure for EB. Medical treatment primarily involves meticulous wound care and dressing, nutritional support and symptomatic relief of pain and itch. Clinical research (CR) into EB is currently active in a variety of potential treatment domains, including protein, cell, gene and drug therapies. This phenomenon, by undertaking preliminary investigations into attitudes and perceptions towards CR, within the global EB community.

METHODS

This research was conducted during the period of May-August, 2014, under the auspices of DEBRA Ireland, on behalf of DEBRA International. DEBRA is a patient organisation that focuses on patient care and research. There are numerous national DEBRA organisations around the world and they come together under the umbrella of DEBRA International.

The aim of the study was to gather information from both clinical researchers involved in EB and people living with EB about their experiences of clinical research and their attitudes towards clinical trials. As well as this, factors involved in patients’ and their families’ decisions to take part in clinical trials were to be investigated. DEBRA has a central position as a trusted advocate in this community, which facilitated the engagement of participants in the study.

An explanatory mixed-methods approach was adopted. As a first step, the views of researchers were explored through interviews. The themes emerging from this qualitative phase were then used to guide the design of a survey to explore the views of patients in a quantitative manner.

INTERVIEWS

Twenty-four senior investigators with experience in EB clinical research were contacted in May and June of 2014. These investigators were either known to be involved in past or active clinical trials and/or were listed as investigators on the main clinical trial registries. Thirteen responded and eleven of these were interviewed. The interviews took place over the phone or via Skype®. Ten open-ended questions were used to guide each conversation in a semi-structured manner. These questions were made available to each participant beforehand.

Confidentiality was assured at the beginning of each interview. Consent to record the interview and for opinions to be published on an anonymous basis was requested. Each person was encouraged to raise any additional topics or points of information during the course of the conversation. Interviewees were asked questions on a range of topics, including their experiences of recruiting patients, the particular issues for EB patients participating in CR and the role DEBRA might play in supporting recruitment. Interviewees were asked to consider the topics from their perspective as both a researcher and a patient.
The survey was designed on the basis of the outcomes of the interviews, the experiential knowledge of DEBRA representatives and the literature relating to general populations. It was made available in English, so a good proficiency in this language was required. Requests were made to some DEBRA representatives internationally for assistance in spreading awareness of the survey. It was noted that the fact that they survey was disseminated through DEBRA channels, and that the participants were self-selecting, might introduce selection bias. That is, those participating were likely to have a prior interest in the topic and to be positively disposed towards DEBRA.

The preamble to the survey contained information about the purpose of the study, what the results would be used for and assured participants of confidentiality. Moving from the introduction to the body of questions implied consent for results to be used in analysis. The survey was hosted on SurveyMonkey Inc. (www.surveymonkey.com). It was publicly available from June to August. Respondents were asked nine questions in total; three of these provided the background of the respondent; one asked about their previous experience with clinical trials; two asked about where they would source information; two asked to rank the relative weight of factors in their decision-making process. Questions took a variety of formats, including open questions and fixed response questions, some of which incorporated 5-point Likert scales. There was a total of 43 respondents to the survey. The full text of the survey is presented in Table 1.

At close of the project, data was downloaded from the hosting website and responses were analysed. The results of the survey were then considered on their own merit and in consideration of the themes emerging from the researcher interviews.

### Table 1: Detail of survey questions and answers

<table>
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<td>1. Which option best describes you?</td>
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<td>43/43 (100%)</td>
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<td>2. Which of the following best describes the severity of your EB?</td>
<td>Multiple choice</td>
<td>• Mild&lt;br&gt; • Moderate&lt;br&gt; • Severe&lt;br&gt;</td>
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The themes that emerged were used to define a focus of questioning for the second, quantitative phase of the study.

**SURVEY**

The survey was designed on the basis of the outcomes of the interviews, the experiential knowledge of DEBRA representatives and the literature relating to general populations. It was made available in English, so a good proficiency in this language was required. Requests were made to some DEBRA representatives internationally for assistance in spreading awareness of the survey. It was noted that the fact that they survey was disseminated through DEBRA channels, and that the participants were self-selecting, might introduce selection bias. That is, those participating were likely to have a prior interest in the topic and to be positively disposed towards DEBRA.

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RESULTS

INTERVIEWS
Three major themes emerged from analysis of the content of the interviews with EB clinical researchers. These represent attitudes and ideas that are held across the spectrum of those interviewed. However, in a small community such as EB, the outliers that may not be represented by broad themes are proportionally very important. As such, this analysis does not purport to be exhaustive.

Theme 1: EB clinical research is more challenging than expected by those involved

Many positive enabling factors exist for EB clinical research. These include:

- A good, communicative relationship between EB patients and their clinicians;
- A patient and family cohort who are quite medically literate and willing to engage;
- A motivated network of researchers.

However, on balance, the experience of CR is seen to be more challenging than straightforward. Pervasive negative factors and challenges exist, such as:

- Many subtypes of EB, which complicates study design;
- Limited current evidence on the natural history of EB;
- Patients are small in number and geographically scattered;
- High burden of disease on the patient;
- Lack of up-to-date and quality registries;
- Issues with coordination between different clinics, in some cases.

In addition to these challenges, there was some mention of particular challenges with regulatory bodies and other groups, such as insurance companies. These references were noted, but not explored in detail.

Theme 2: Heterogeneity of opinion of patients towards research

The researchers reported a diversity in the attitudes to clinical research among patients. One line hand, most reported engaging with patients who were consistently interested and keen to be involved. On the other hand, many had also encountered patients who would not - or often, could not - take on the extra burden of being engaged in research.

All researchers acknowledged that face-to-face communication, such as taking extra time with patients in clinic to explain more about research, or a particular trial opportunity, might help to positively change attitudes to CR. Other opportunities to spread information about research, such as speaking at conferences, were also viewed as having a positive effect, although most also expressed an opinion that this was not frequently feasible. This type of sentiment was suggestive of a sense of frustration within the EB research community as well. Researchers appear to be aware that flexible, creative methods may help overcome some challenges, but these are seen as unrealistic due to resource constraints. Overall, clinicians were aware that they would have to adapt and be flexible when undertaking EB clinical research.

Theme 3: The central role of community and collaboration

The idea of there being an EB "community", "world" or "network" was a strong theme across the interviews. It is generally considered to consist of patients and their families at the centre, with DEBRA, clinicians and researchers beside them.

It appears to be agreed opinion that patients and their advocates must be involved in clinical research efforts on an equal standing to the researchers, if clinical research is to be successful. Researchers' efforts tended to be more fruitful when they collaborated with DEBRA, clinicians and researchers beside them.

Most people directly mentioned community in their final comments. This was most frequently expressed in the context of a desire for more unity and collaboration, particularly within the medical community, and between the medical community and patient. The next most frequently mentioned sentiment was in praise of ongoing community building efforts.

SURVEY

Of the total number of survey respondents (43), 39.53% were people with EB and 48.8% were parents of children with EB (it was not specified how many of their children were affected). Mild and moderate EB were the most common severities of EB cited (64.2% and 41.9%, respectively). The geographical locations of respondents spanned five continents.

Only 9.3% of respondents reported having taken part in a clinical trial. The majority of people (76.7%) expressed a willingness to participate in a clinical trial; 34.88% of these reported to be "very eager" to take part and 41.86% reported they would "consider taking part with reservations". Only 1 respondent (2.3%) chose the explicitly negative option of "I would never take part in an EB clinical trial"; however, with a small sample as this, such responses should not be deemed insignificant.

In responding to Question 5, on where respondents would go for information on EB clinical trials, DEBRA was the most commonly quoted source of information for EB clinical trials (26 mentions of 63 total), followed by search engines ("internet" or "Google"); 16 of 63). Medical personnel (dermatologists, nurses or clinics) were mentioned as "world" or "network" was a strong theme across the interviews. It is generally considered to consist of patients and their families at the centre, with DEBRA, clinicians and researchers beside them. However, in a small community such as EB, the outliers that may not be represented by broad themes are proportionally very important. As such, this analysis does not purport to be exhaustive.

In total, 37 of the 43 respondents completed Questions 6 to 8. Responses to the following three questions: “To what extent would the following factors POSITIVELY/NEGATIVELY influence your decision to take part in an EB clinical trial?” and “To what extent would you trust information from the following people/groups, in considering whether to participate in an EB clinical trial?” are presented in Tables 2, 3 and 4.

Question 6 asked about factors that would positively influence a decision to participate in an EB clinical trial. The vast majority (75%; n=319) of scale points chosen across all options were either "very strong" or "strong" influence. 94.5% listed symptom relief as either a "very strong" or "strong" influence, compared with 89.1% for the possibility of finding a cure. Access to the trial intervention after completion of the study was the next most influential factor, with 78.3% of responses showing it was either "very strong" or "strong" influence.
The possible role of a placebo (a substance with no therapeutic effect) was found to be the treatment of choice for the duration of the trial. Access to the treatment/ intervention, following completion of the trial, was a significant influencing factor (29.73% (11) 16.22% (6) 18.92% (7) 5.41% (2)). The likelihood of receiving expert medical care for the duration of the trial was also a strong influence (41.67% (15) 27.08% (10) 19.44% (7) 8.33% (3)). The possibility of a major risk of travel expenses was also rated as a strong influence (29.73% (11) 16.22% (6) 18.92% (7) 5.41% (2)).

The knowledge that it was difficult to recruit enough patients to ensure the trial’s successful completion was also rated as a strong influence (36.11% (13) 33.33% (12) 19.44% (7) 5.56% (2)).

Responses to Q.7, “To what extent would you trust the following information from an EB clinical trial?”, are seen in Table 2.

**DISCUSSION**

Prior to this study, the evidence relating to the attitudes and opinions of researchers and patients towards CR in EB was primarily anecdotal. Being a small community with a strong network, such evidence should not be discounted. However, this study aimed to add to understanding of the attitudes to EB clinical research by objective investigation.

The anecdotal evidence indicated that patient engagement and participation in EB clinical research is a particular issue; as such, it was chosen as a central theme for this research. The qualitative portion of this research acted as an exploratory phase, from which additional themes emerged. The semi-structured approach taken allowed these new themes to emerge, as well as allowing specific questions to be answered. Much information and insight into attitudes to CR was garnered in this way.

It would be inappropriate to try and label researchers’ attitudes to CR as wholly “positive” or “negative” in the context of EB. The general attitude is both broadly positive and negative – positive in the sense that there is a great sense of motivation from curative to localised symptom management. Some researchers expressed a strong altruistic motivation to participate. This demonstrates a strong altruistic motivation to participate.

The three themes that emerged on analysis of the interviews with researchers are reflective of the more heterogeneous, in terms of experience and of opinion. The three themes that emerged on analysis of the research acted as an exploratory phase, from which additional themes emerged. The semi-structured approach taken allowed these new themes to emerge, as well as allowing specific questions to be answered. Much information and insight into attitudes to CR was garnered in this way.

The knowledge that it was difficult to recruit enough patients to ensure the trial’s successful completion was also rated as a strong influence (36.11% (13) 33.33% (12) 19.44% (7) 5.56% (2)).

The quantitative portion of the study investigated patients’ and their families’ attitudes towards CR, with a particular focus on the factors that influence their participation. As such, the results of the survey provide good data on what factors are involved in a decision to participate. Motivation levels and perceptions are also probed in this question set, but in an indirect way.

The overwhelming positive tendency in responses to Question 6, on factors that positively influence participating in clinical trials (Table 2), was interesting to note. This consistent trend to list factors as “Very strong” or “Strong” influences suggests that patients are open to the idea of many types of research, from curative to localised symptom management. This is indicative of a general open-minded, positive attitude towards CR. As well, the advancement of medical knowledge into EB was consistently rated as a very positively influencing factor. This demonstrates a strong altruistic motivation to participate.

Understandingly however, factors with the potential to positively influence the patient’s own health are of foremost consideration.

As mentioned previously, Question 7 asked about negative factors involved in decision making. Here, answers lacked the trend towards positive scale points seen for Question 6, with more of a central

<table>
<thead>
<tr>
<th></th>
<th>Very strong influence</th>
<th>Strong influence</th>
<th>Moderate influence</th>
<th>Weak influence</th>
<th>No influence</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>The possibility of a cure</td>
<td>78.38% (29)</td>
<td>10.81% (4)</td>
<td>5.41% (2)</td>
<td>2.7% (1)</td>
<td>2.7% (1)</td>
<td>(37)</td>
</tr>
<tr>
<td>The possibility of relief from symptoms</td>
<td>75.68% (28)</td>
<td>18.92% (7)</td>
<td>2.7% (1)</td>
<td>0% (0)</td>
<td>2.7% (1)</td>
<td>(37)</td>
</tr>
<tr>
<td>The potential to contribute to the advancement of EB medical knowledge</td>
<td>40.54% (15)</td>
<td>29.73% (11)</td>
<td>16.22% (6)</td>
<td>10.81% (4)</td>
<td>2.7% (1)</td>
<td>(37)</td>
</tr>
<tr>
<td>Having the costs of participation covered, e.g. travel expenses</td>
<td>29.73% (11)</td>
<td>29.73% (11)</td>
<td>16.22% (6)</td>
<td>18.92% (7)</td>
<td>5.41% (2)</td>
<td>(37)</td>
</tr>
<tr>
<td>The likelihood of receiving expert medical care for the duration of the trial</td>
<td>41.67% (15)</td>
<td>27.08% (10)</td>
<td>19.44% (7)</td>
<td>8.33% (3)</td>
<td>2.78% (1)</td>
<td>(36)</td>
</tr>
<tr>
<td>Access to the treatment/ intervention, following completion of the trial</td>
<td>45.95% (17)</td>
<td>32.43% (12)</td>
<td>16.22% (12)</td>
<td>0% (0)</td>
<td>5.41% (2)</td>
<td>(37)</td>
</tr>
<tr>
<td>The knowledge that it was difficult to recruit enough patients to ensure the trial’s successful completion</td>
<td>36.11% (13)</td>
<td>33.33% (12)</td>
<td>19.44% (7)</td>
<td>5.56% (2)</td>
<td>5.56% (2)</td>
<td>(36)</td>
</tr>
</tbody>
</table>

**Table 1** Responses to Q.6, “To what extent would the following factors positively influence your decision to take part in an EB clinical trial?”

<table>
<thead>
<tr>
<th></th>
<th>Very strong influence</th>
<th>Strong influence</th>
<th>Moderate influence</th>
<th>Weak influence</th>
<th>No influence</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>The possibility of a minor risk to health</td>
<td>29.73% (11)</td>
<td>21.62% (8)</td>
<td>29.73% (11)</td>
<td>13.51% (5)</td>
<td>5.41% (2)</td>
<td>(37)</td>
</tr>
<tr>
<td>The possibility of a major risk to health</td>
<td>64.66% (24)</td>
<td>24.32% (9)</td>
<td>8.11% (3)</td>
<td>2.7% (1)</td>
<td>0% (0)</td>
<td>(37)</td>
</tr>
<tr>
<td>The possibility of being given a placebo (a substance with no therapeutic effect)</td>
<td>27.03% (10)</td>
<td>24.32% (9)</td>
<td>29.73% (11)</td>
<td>5.41% (2)</td>
<td>13.51% (5)</td>
<td>(37)</td>
</tr>
<tr>
<td>The need for painful procedures during the trial, e.g. injections, biopsies</td>
<td>29.73% (11)</td>
<td>35.14% (13)</td>
<td>18.92% (7)</td>
<td>8.11% (3)</td>
<td>8.11% (3)</td>
<td>(37)</td>
</tr>
<tr>
<td>The treatment being limited or localised, e.g. treating only 1 or 2 wounds</td>
<td>10.81% (4)</td>
<td>16.22% (6)</td>
<td>32.43% (12)</td>
<td>16.22% (7)</td>
<td>21.62% (8)</td>
<td>(36)</td>
</tr>
<tr>
<td>The need to attend clinics other than your usual ones</td>
<td>10.81% (4)</td>
<td>13.51% (5)</td>
<td>27.03% (10)</td>
<td>24.32% (9)</td>
<td>24.32% (9)</td>
<td>(36)</td>
</tr>
<tr>
<td>The need to travel a long distance to the trial centre</td>
<td>21.62% (8)</td>
<td>13.51% (5)</td>
<td>29.73% (11)</td>
<td>16.22% (6)</td>
<td>18.92% (7)</td>
<td>(37)</td>
</tr>
<tr>
<td>The need to visit the trial centre at 2-weekly intervals</td>
<td>10.81% (4)</td>
<td>24.32% (9)</td>
<td>32.43% (12)</td>
<td>10.82% (4)</td>
<td>21.62% (8)</td>
<td>(37)</td>
</tr>
<tr>
<td>The need to visit the trial centre at monthly intervals</td>
<td>2.7% (1)</td>
<td>21.62% (8)</td>
<td>27.03% (10)</td>
<td>27.03% (10)</td>
<td>21.62% (8)</td>
<td>(37)</td>
</tr>
<tr>
<td>The need to revisit the trial centre at 3-monthly intervals</td>
<td>2.7% (1)</td>
<td>8.11% (3)</td>
<td>32.43% (12)</td>
<td>27.03% (10)</td>
<td>29.73% (11)</td>
<td>(37)</td>
</tr>
</tbody>
</table>

**Table 2** Responses to Q.7, “To what extent would you trust the following information from an EB clinical trial?”

<table>
<thead>
<tr>
<th></th>
<th>Would definitely trust</th>
<th>Would likely trust</th>
<th>Would cautiously trust</th>
<th>Would probably not trust</th>
<th>Would definitely not trust</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your primary doctor</td>
<td>40.54% (15)</td>
<td>21.62% (8)</td>
<td>24.32% (9)</td>
<td>10.81% (4)</td>
<td>2.7% (1)</td>
<td>(37)</td>
</tr>
<tr>
<td>Your family</td>
<td>37.84% (14)</td>
<td>21.62% (8)</td>
<td>24.32% (9)</td>
<td>13.51% (5)</td>
<td>2.7% (1)</td>
<td>(37)</td>
</tr>
<tr>
<td>Other families with EB</td>
<td>25% (9)</td>
<td>38.89% (14)</td>
<td>30.56% (11)</td>
<td>2.78% (1)</td>
<td>2.78% (1)</td>
<td>(36)</td>
</tr>
<tr>
<td>Social networks with a focus on EB</td>
<td>5.41% (2)</td>
<td>46.65% (18)</td>
<td>32.43% (12)</td>
<td>5.41% (2)</td>
<td>8.11% (3)</td>
<td>(37)</td>
</tr>
<tr>
<td>DEBRA</td>
<td>55.56% (20)</td>
<td>38.89% (14)</td>
<td>5.56% (2)</td>
<td>0% (0)</td>
<td>0% (0)</td>
<td>(36)</td>
</tr>
</tbody>
</table>
tendency. Thus, on a relative scale, the degree of influence exerted by positive factors outweighs the influence of negative factors (Table 3.4). This suggests that positive factors play a more decisive, stronger role in decision making than negative factors. The one strong exception to this was the possibility of a major risk to health which was rated as having a strongly negative influence on the decision to participate in a clinical trial. In this case, only 3 respondents suggested that it would not be a “very strong” or “strong” negative influence. This risk aversion is not surprising - the decision making process can be seen to be akin to a risk/benefit analysis. However, the higher the possible risk, the higher the possible gain must be to overcome that barrier.

The survey data on perceived trustworthiness of different information sources provided some interesting, but not entirely surprising, insights. Primary doctors were considered only slightly more trustworthy than family members as an information source on clinical trials. This is perhaps indicative of the fact that primary care specialists are rarely expert in a complex condition like EB. DEBRA was viewed as a highly trustworthy source of information; this should be viewed cautiously, in consideration of the fact that all respondents were recruited through engagement with the charity. One of the most interesting findings here is the general positive attitude towards information received from social media networks, with almost half the respondents reporting that they would trust EB social networks. The role of social media in clinical trials is a new and growing phenomenon that needs further attention. It holds the possibility of being of massively beneficial or hugely detrimental to CR; vested interests need to be actively aware of what is happening on social media, in order to reduce the likelihood of the latter occurring. Other social networks, such as other families with EB, also play an important role in the dissemination of information. Again, this is not surprising in a small and close community. However, such dissemination can be troublesome if the information itself is not accurate.

One conclusion that can be drawn from the combined results of the interviews and survey is that patient attitudes are very variable. Reports from interviews suggest that there are two main cohorts of patients. One is highly motivated and positively predisposed; they will consistently find and engage with research, be that by general support or active participation. The other cohort consistently do not want to participate and cannot be convinced, in large part, due to the daily burden of the disease. The survey results do not contradict this. It is positive to note that there is a well engaged and informed cohort; similarly, it is disappointing to note that there is a well-populated cohort that seem to be struggling with the daily pressures of living with EB. Here is where advocacy groups can play a very important role.

Those who are struggling need critical support in their day to day lives; those who want to engage with research need to be supported in their own way as well.

It is likely that most who participated in the survey are interested in CR; as such, the other segment of the patient population, mentioned above, are unlikely to be well represented in these results. It is important that this cohort is engaged with in exploring these topics, to get a complete picture of what opinions to CR are and what drives participation.

LIMITATIONS

It should be made clear that this study does not aim to be comprehensive. The findings are to be used by DEBRA and others as a basis for further research, and as a starting point from which solutions to problems can be found. Themes which were not possible to explore in-depth in this study, such as the researchers’ experiences of engaging with regulators and the implications of cross-border collaboration, are areas in need of further investigation.

There are limitations to this piece of research, the vast majority of which were anticipated before the project commenced. Chief among these was the limited timeframe available for data collection and the small sample sizes.

CONCLUSIONS

Clinical research into epidermolysis bullosa is known to be a challenging endeavour. We aimed to investigate the attitudes towards clinical research within the community, by engaging medical researchers, and patients and families. Attitudes within the community are not homogenous, but among those who are positively predisposed, motivation levels are high and consistent. Patient participation poses a particular challenge for the progress of clinical trials. The barriers to this are well recognised by all, but they are not insurmountable. Engagement with clinical research is seen in the light of perceived risks and benefits. Efforts should be made to educate people as to what the actual risks and benefits are, as well as minimising risk and maximising benefits for patients and families, where possible.
Emergency Medical Services & Emergency Medical Science - Where Now?

Written by Prof. Gerard Bury, MD, FRCPI, MRCGP, MICGP

Professor of General Practice

Director of the UCD Centre for Emergency Medical Science (CEMS)
A CASE STUDY

A small town in Ireland – in Sligo or Kerry, Wicklow or Donegal... Mr. Kelly, a man in his 70s, complains of central chest pain and becomes very unwell. His distressed wife has called their daughter Emma to come and help; while they are talking, Mr. Kelly slumps to the floor, becomes unresponsive and appears to stop breathing.

What care will he receive? Situations like this arise every day and are managed by a well functioning emergency care system with volunteers and professionals working closely together.

Emma phones 999 and is connected to the National Ambulance Service (NAS) Control Centre, recently centralised to a high-tech site in Tallaght, County Dublin. A call-taker takes brief details before recognising that the situation she describes may well be a cardiac arrest, coded as ‘9Echo1’ (the highest priority) on the internationally standardised Advanced Medical Priority Dispatch System (AMPS) used to manage all calls. As soon as the code appears on the computer system, a dispatcher at a nearby desk begins to allocate resources while the call-taker continues to talk to Emma.

The Computer Aided Dispatch system indicates available ambulances and Rapid Response Vehicles in the area and also automatically identifies and alerts volunteer Cardiac First Responders or nearby participating GPs who may be in a position to reach Mr. Kelly before an NAS crew. While the dispatcher juggles these assets, the call-taker asks Emma to re-check her father and then gives simple instructions on how to do compression-only CPR.

A local GP is making a housecall nearby when she receives the alert and goes to Mr. Kelly’s house immediately – Emma is doing CPR reasonably well and continues while the GP opens her Advisory External Defibrillator (AED) and attaches the adhesive pads to his chest. He is in Ventricular Fibrillation (VF) – she delivers the initial shock and immediately resumes CPR. At that point, a volunteer Cardiac First Responder from the local group arrives and they begin two-person CPR, using an airway adjunct. As they deliver a second shock, an ambulance arrives with an Advanced Paramedic crew member; the second shock produces a return of spontaneous circulation and soon afterwards, Mr. Kelly’s blood pressure is measured at 90/70, his heart rate is 68/min and regular and his SpO2 is 95%. A 12 lead ECG shows an anterior ST elevation myocardial infarction (STEMI).

There is excellent evidence that early Percutaneous Coronary Intervention (PCI), carried out within two hours of onset of a STEMI, is the best treatment in terms of survival and long term benefit. Since 2012, Ireland has had six hospitals providing round-the-clock PCI facilities in their interventional cardiology departments; the key challenge is to reach that centre within two hours of the first ECG to show STEMI changes. In many parts of Ireland, that time-critical deadline is met by the joint NAS / Irish Air Corps Emergency Aeromedical Service, introduced in 2012. If a land ambulance is unlikely to get Mr. Kelly to the nearest centre within those two hours, the Air Corps AW139 will be tasked to do so. With a crew that includes an NAS Advanced Paramedic, Mr. Kelly will receive ongoing monitoring and analgesia during his trip to hospital; the GAA pitches of most towns and villages around Ireland have been mapped and act as informal landing sites for the helicopter, which has successfully completed hundreds of such missions during its trial period in this role.

PERFORMANCE AND CHANGE

Mr. Kelly’s case study is a realistic narrative of high quality care delivered to many patients in recent years. However, it’s not the full story. As our country and health service struggle with painful financial restrictions and major structural changes, the NAS and the broader EMS community have faced many challenges. In recent months, the Health Information and Quality Authority (HIQA) has published two reports on aspects of our pre-hospital emergency care systems; key weaknesses were identified and recommendations for improvement set out.2 Two further reports due early in 2015 will explore the capacity and capabilities of the NAS and its longterm relationship with Dublin Fire Brigade, which provides emergency ambulance services to most of Dublin City.

Our ambulance services comprise a key part of the emergency medical system but other components are also vital. Our hospital systems and particularly their Emergency Departments have experienced major changes in funding, organisation and roles which have significant implications for the communities they serve. Community services, including general practice and lay volunteers have also had clear recognition of their roles and potential.

KEY PERFORMANCE INDICATORS

So what has HIQA said in its analysis? Overall, HIQA says it has concerns about NAS performance. In all parts of our healthcare system, performance measurement should be an integral part of how we work and learn – it must be a tool to help us improve, not a stick with which to beat individuals.

Much therefore depends on how we measure performance.

HIQA highlights an Emergency Medical Services (EMS) system which relies on ‘legacy’ structures and procedures and which has much work to do to become a uniformly high quality provider of care to all of its patients, all of the time. HIQA expresses concern about the poor record of the NAS in meeting the time targets for emergency responses to 999 calls, reporting that in a 15 month period, only 58% of the most critical calls – Echo calls, received a response within eight minutes and only 34% of the next most serious category – Delta calls, received a response in the same time period.

However, is HIQA itself part of the problem? During much of 2010 and 2011, the NAS, HIQA and the Pre-Hospital Emergency Care Council (PHECC) worked together on the development of Key Performance Indicators (KPIs) for EMS. There is general acceptance that KPIs must have to offer all health care services and the communities we serve – however, they should be valid (measure what it important) and reliable (offer consistent results). In 2011, HIQA formally required the NAS to introduce time-based targets, as the only measure of its clinical performance – essentially, to ensure that 75% of Echo calls received a response within eight minutes. A timely response is obviously critically important in cardiac or respiratory arrest but it is not the sole determinant of the quality of care provided. Paradoxically, a cardiac arrest patient who receives an EMS response at nine minutes and is resuscitated from VF (perhaps Mr. Kelly?) is counted as an inadequate performance issue by HIQA, whereas a similar patient who receives a response in seven or eight minutes but is not resuscitated, is a success story. Both NAS and PHECC strongly advised HIQA at the time that time-based targeting by itself is a poor measure of the performance of such a complex clinical service and that clinical KPIs should be introduced in parallel.1 HIQA chose to rely solely on time targets – its recent report is influenced heavily by performance against those targets but also accepts that clinical KPIs have a role in the future.

Many such clinical KPIs can be identified and are likely to be introduced by individual EMS services in Ireland and elsewhere in coming years (aspirin and ticagrelor for STEMI, control of seizures on scene, treated hypoglycaemia, adequate pain relief etc). However, if the public (and the statutory regulator of health service quality) continue to rely on surrogate measures of performance which have limited validity, then confidence in the EMS system may continue to fall.
EMERGING CHALLENGES FOR EMS

Emergency medical science and emergency medical services in Ireland face complex challenges in the coming decade. The more obvious include:

- Scientific and technological change in healthcare
- Demographic change
- Funding and organisational constraints
- Expectations and awareness of the public
- Integration with the broader healthcare system
- Command, control and dispatch systems
- Clinical KPIs and standards
- Scope of practice, education and Continuous Professional Development (CPD)
- Governance and leadership: responsive or pro-active?

Change to improve meaningful performance (clinical care) must be our goal. Much has changed in Irish EMS in the last decade and our systems are unrecognisable from those of two decades ago. But as the cliché says, much remains to be done. Appropriate change in systems and clinical practice will hopefully gather pace in the short term - some examples may illustrate the changes on the way:

1. SCOPE OF PRACTICE

Paramedics and Advanced Paramedics now deliver care that, until a few years ago, was the exclusive domain of registered medical practitioners and which required equipment and skills only available in specialist hospital units. Defibrillation, cardioversion and STEMI thrombolysis are among those skills; potent pain relief, reversal of hypoglycaemia and seizure control are among the pharmacological interventions available. Understandingly, the rapid evolution of education, skills and Clinical Practice Guidelines has focused on ‘high acuity’ problems which threaten life or limb. The next major shift in scope of practice may involve a re-focusing on those clinical problems dealt with by EMS which are ‘low acuity’ but very common. Some overseas ambulance services deal with up to 40% of their callers without sending an emergency ambulance - callers may receive advice, be referred to an alternative service (such as their GP or an out-of-hours service) with an appointment or be dealt with on a non-emergency basis.

2. PARAMEDIC EDUCATION

Traditionally (certainly for the last 50 years), Paramedics in the UK and Ireland have been trained after they join the workforce, by the services which employ them. The inadequacies of this strategy have been well recognised, so that in the UK, by 2019, every Paramedic joining the workforce will be the graduate of a university programme (of three or four years’ duration) which is closely aligned with the education of doctors, nurses and other healthcare professionals.

The introduction of third level education for future Paramedics in Ireland is less clear. UCD Centre for Emergency Medical Science (CEMS) has proposed the introduction of such pathways to government and UCD has accredited a four year Honours BSc Emergency Medical Science programme - however, its adoption as an option for those entering university is subject to government decisions on funding and how the NAS should adapt to such change. When introduced, these programmes will incorporate the care of high and low acuity illness and injury, the use of complex interventions and a closer integration of Paramedics into the education and Continuous Professional Development frameworks used by other healthcare professions.

Expert Article

Prof. Gerard Bury
Written by
UCD Student Medical Journal
Emergency Medical Services & Emergency Medical Science - Where Now?

22 23
3. COMMUNITY INTEGRATION
Since 2006, UCD CEMS has run the Medical Emergency Responders: Integration & Training (MERIT) Project which has equipped and trained more than 500 general practices around Ireland to deal with cardiac arrest in the community. The investment of more than €3 million by HSE, Department of Health and PHECC in this project represents one of the biggest research investments in general practice in Ireland in the last decade - and has paid off handsomely. We recently reported that general practice in Ireland in the last decade – Department of Health and PHECC in this project.

The training of more than 500 general practices around Ireland to deal with cardiac arrest in the community. The rapid development of a network of local volunteer responders is a key recommendation from the Health Technology Assessment of Public Access Defibrillation. HIQA, 2014.

4. HOSPITAL GROUPS
In 2013, the government announced a major re-structuring of the country’s hospital system, by creating six networks each essentially centred on one of Ireland’s six medical schools. The intention is to ultimately have a number of trusts which have a good deal of scope to address the needs of the populations they serve as efficiently as possible. It also implies that each trust may develop its own methods to address those needs, including the care of emergencies. It may therefore offer opportunities for emergency medical science to research new ways to offer such care.

‘Transport medicine’ has already been identified as a key innovation. With the reduction in the number of Emergency Departments which take emergency ambulances from more than 40 to around 20, patients with complex problems are being cared for for longer periods. Patients who are very unwell are also being transferred from smaller hospital to a small number of specialist national units. The science, logistics and training needed to deliver these diverse forms of emergency care are being brought together, under the auspices of the PHECC and will provide a novel expertise within the EMS family.

IN CONCLUSION
Both emergency medical science and emergency medical services are vibrant and central components of our health services. The challenges and opportunities they present make them increasingly central to academic medicine. Mr. Kelly’s case is an example of the high quality care we can deliver – we now need to make sure we deliver that standard of care to whoever needs it, whenever or wherever they are.

UCD Centre for Emergency Medical Science
UCD CEMS was established in 2001 (under a different name) as a teaching, research and innovation centre. CEMS is a unit within Academic General Practice at School of Medicine & Medical Science (SMMS) and grew from our beginnings as the only unit in Ireland delivering Immediate Care training to Irish GPs – we continue to deliver about 400 training places for courses in cardiac, trauma and paediatric care each year. MERIT (Medical Emergency Responders: Integration & Training) has greatly strengthened our Immediate Care teaching by linking teaching to the delivery of care in cardiac arrest and the collection of high quality research data. This is one key part of our research activities.

CEMS is the only unit in Ireland accredited to provide both Paramedic (DipEMS) and Advanced Paramedic (GradDipEMS) training, in association with our partners, the HSE National Ambulance Services College. More than 1,500 Paramedics and Advanced Paramedics have graduated from our programmes. The establishment of two MScEMS programmes (one for APs and one for Doctors, Nurses and Paramedics) has broadened our range of teaching opportunities.

CEMS also takes responsibility for components of the undergraduate medicine programme by accrediting all students in BLS and delivering an intense course in emergency care skills in the Professional Completion Module of final semester.

We work closely with partners in the HSE, NAS, Dublin Fire Brigade; Defence Forces and many others; we look forward to working with colleagues and students throughout UCD to bring Emergency Medical Science to a wider audience.

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05 The Establishment of Hospital Groups as a Transition to Independent Trusts. Department of Health, 2013.

** All photos were provided by UCD CEMS and portray Emergency First Responders in training.
Gestational Weight Gain and Gestational Diabetes Mellitus: Popular Beliefs and Emerging Evidence

Written by Lisa A O’Higgins, Dr. Amy C O’Higgins, Sophie Gray, Thomas McCartan, Dr. Ann Rowan, Dr. Anne Fennessey, Prof. Michael J Turner

UCD Centre for Human Reproduction, Coombe Women and Infants University Hospital, Dublin 8, Ireland

Gestational Weight Gain, Gestational Diabetes Mellitus, Foetal Growth, Maternal Obesity

Keywords

Review Article

# 1

Gestational Weight Gain and Gestational Diabetes Mellitus: Popular Beliefs and Emerging Evidence
ABSTRACT

The aim of this article is to review the evidence on gestational weight gain (GWG), and its relationship between abnormal foetal growth and the development of gestational diabetes mellitus (GDM). Maternal obesity is a major concern of modern obstetrics and is associated with increased maternal and foetal complications. It is becoming increasingly common and GWG has attracted an upsurge of interest.

In 2009, recommendations from the Institute of Medicine in the United States revised downwards the weight gain recommendations in pregnancy for obese mothers. There is no international consensus or guidelines on GWG. There are concerns with evidence on GWG and many publications have methodological shortcomings.

INTRODUCTION

Maternal obesity is a major concern in modern obstetrics. It is increasingly common, is associated with additional risks for both mother and baby and gives rise to added costs to the health services. The subject of gestational weight gain (GWG) has attracted an upsurge of interest in recent years, particularly as the prevalence of maternal obesity is increasing. It is in this context that this article aims to review the evidence on the relationship between GWG, abnormal foetal growth and the development of gestational diabetes mellitus (GDM).

In 2009, the Institute of Medicine (IOM) in the United States published a review of all existing evidence on GWG. It revised GWG guidelines based on pre-pregnancy body mass index (BMI) independent of age, parity, smoking history, race, and ethnic background. The focus of previous guidelines had been on the attainment of adequate weight gain in pregnancy so as to minimise foetal and neonatal complications. The newer publication attempted to provide guidance on the balance between weight gain in pregnancy and outcomes for both mother and baby. This shift of emphasis, taking into account the possible negative outcomes associated with excessive weight gain, resulted in recommended weight gain for obese women during pregnancy being revised downwards. These guidelines were based on the US population only. There has been no international consensus on recommendations for GWG.

CONCERNS WITH THE CURRENT EVIDENCE

Many publications on GWG have methodological shortcomings. Studies on GWG to date have been fraught with difficulties and high quality scientific evidence is lacking. The IOM report acknowledged that, "Unfortunately, most of the data available to the Committee was not collected with a high level of rigor and most studies relied on recall weight values" (chapter 2, IOM 2009). The accuracy of self-reported weight was reviewed in 32 studies involving 57,172 women, and in each study, women underestimated their weight. Self-reported weight leads to faulty categorisation of BMI in 22% of cases and has led to the diagnosis of obesity being missed in 5% of cases. Studies based on self-reporting of maternal weight both under-diagnose obesity and exaggerate the risk of obesity because women with mild obesity report themselves in the overweight category.

There is the additional problem of timing in the calculation of maternal BMI. In the reported studies there is wide variance in the times when BMI is calculated. Some studies utilised the last measured weight before pregnancy while others utilised the first recorded weight in pregnancy. Pre-pregnancy weight has not been defined and in women who are anovulatory a change in weight may stimulate ovulation. For example, ovulation is promoted by weight gain in underweight women and by weight loss in those with polycystic ovarian syndrome.

During pregnancy weight is dependent on gestational age and assessment of weight therefore requires knowledge of gestational age. A study of 1,000 women in early pregnancy showed no change in mean weight or body composition during the first trimester. Measuring weight gain obviously requires the measurement of weight at two different time points. A problem arises with the timing of the repeat measurement in pregnancy. Some studies have used the last measured weight in pregnancy, without account being taken of the importance of gestational age.

In previous studies pregnancies were not dated accurately by ultrasound and so the gestational age at the time of the BMI calculation not known. Some, such as the landmark Hyperglycaemia and Adverse Pregnancy Outcome (HAPO) study, calculated BMI only as late as 24.32 weeks gestation. At this gestation, BMI does not reflect that of early pregnancy and analysis of clinical outcomes cannot distinguish between the influence of BMI and pregnancy weight gain in the second trimester. Gestational age is an important determinant not only of GWG itself but also of the clinical outcomes of GWG. Therefore clinical outcomes can only be compared when there is accurate knowledge of gestational age. This is particularly important when examining outcomes such as birth weight or babies classed as small-for-gestational age (SGA) or large-for-gestational age (LGA). Early pregnancy dating by ultrasound should be a pre-requisite for any accurate study of GWG.
GWG AND ABERRANT FOETAL GROWTH

Associations between GWG and aberrant foetal growth have been reported, with higher weight gain associated with LGA babies and lower weight gain associated with SGA babies. However, since weight gain in pregnancy includes the weight of the baby, it is hard for such women to rank larger babies have increased their weight more than women carrying smaller babies. Such epidemiological associations do not provide evidence of causation.

Despite a significant rise in the prevalence of maternal obesity no increase in the number of babies born with a birth weight in excess of 4.5 kg has been identified. Studies have found, in spite of an increase in the prevalence of obesity there has been an associated decrease in babies with macrosomia. Therefore, recommendations regarding GWG and excessive foetal growth have not been well established.

Emerging evidence demonstrates that birth weight is related more closely to maternal fat-free mass than to maternal fat mass. A positive correlation was found between birth weight and an increase in maternal fat-free mass but not fat mass, in a study of 63 women. Previous studies showed that maternal water gain is predictive of birth weight. A recent study from Dublin reported a correlation between birth weight and maternal body composition in 2618 women studied prospectively. The mothers’ body composition was measured directly using bioelectrical impedance analysis during the first trimester. Multivariate regression analysis found that birth weight correlated significantly with fat-free mass but not fat mass, suggesting that attempts to reduce maternal fat mass during pregnancy are unlikely to decrease birth weight.

Even if evidence for a causal relationship between GWG and aberrant foetal growth were established, interventions in pregnancy targeted at limiting GWG have not been shown to prevent excessive foetal growth. Reviews of interventions aimed at optimizing GWG have concluded that the literature is of poor quality and results are inconsistent.

Micronutrient and macronutrient deficiencies in pregnancy are associated with poorer clinical outcomes for both mother and baby. Interventions focused on losing weight during pregnancy should ensure that the growing fetus is not deprived of essential nutrients as a result. The promotion of weight management programmes based on increasing physical activity may be safer than those focusing on dietary restrictions, with an overall emphasis on the promotion of a healthy lifestyle.

Attention has been drawn to an association between obstetric morbidity and high pre-pregnancy BMI. Obesity in pregnancy is associated with an increased risk of a number of serious adverse outcomes, including miscarriage, foetal congenital anomaly, pre-eclampsia, postpartum haemorrhage, stillbirth and neonatal death. There is a higher caesarean section rate and lower breastfeeding rate in this group of women compared to women with a healthy BMI. Pre-pregnancy interventions for BMI optimisation may therefore be more successful at reducing morbidity than interventions started during pregnancy.

GESTATIONAL DIABETES MELLITUS

Gestational diabetes mellitus (GDM) has been defined as ‘any degree of glucose intolerance with onset or first recognition during pregnancy’. It is strongly associated with maternal obesity and is increasingly common. Potentially it increases morbidity for mother and baby. GDM also carries a major resource-burden for maternity services. Screening recommendations for GDM vary throughout the world; in Ireland the HSE recommends selective screening based on the presence of risk factors. The findings of the HAPO study showing increasing adverse pregnancy outcomes for both mother and baby with increasing levels of maternal glycaemia, even below those defined as the threshold for GDM, led to recommendations lowering the level of glycaemia required for a diagnosis of GDM. These recommendations have been met with some controversy, and while endorsed by the American Diabetes Association, have not been endorsed by the American College of Obstetricians and Gynecologists.
CONCLUSION

GWG is a topic of increased interest however, there are huge gaps in the research and methodological shortcomings of studies and to date little evidence for a causative relationship between GWG and aberrant fetal growth or the development of GDM has been shown. We recommend that strategies promoting healthy pregnancy should focus on providing resources to optimise pre-pregnancy BMI and to promoting a healthy lifestyle in pregnancy rather than focusing on weight gain during pregnancy.

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Considering the Policy of Indefinite Deferral Imposed on MSM Blood Donors in Ireland

Written by Kevin O’Malley
Reviewed by Dr. Sinead McDermott, MB MRCPI FRCPath, Consultant Microbiologist, Beaumont Hospital & Our Lady of Lourdes Hospital, Drogheda
Dr. John Lambert MD PhD, Consultant in Infectious Diseases, Medicine and Sexual Health (GUM), Mater, Rotunda and University College Dublin

UCD School of Medicine and Medical Science, University College Dublin, Belfield, Dublin 4, Ireland

Keywords: Blood, Safety, HIV, MSM, Blood Donation, Donor Deferral, Risk Behaviour
**ABSTRACT**

The Irish Blood Transfusion Service currently enforces a policy of indefinite deferral (lifetime exclusion) on blood donation from Men who have Sex with Men (MSM), a measure introduced in the 1980s in response to the emerging AIDS epidemic. Human Immunodeficiency Virus (HIV) continues to affect disproportionate numbers of the MSM population in Ireland, major advances in serological testing and a greater understanding of high risk sexual behaviour have called into question the indefinite deferral period enforced against MSM. In approaching this issue, various factors will be considered and addressed. To provide context for the current donor screening policies, a brief synopsis of two infamous contamination scandals within the Irish Blood Transfusion Service are provided. Criteria for donor eligibility are examined, as are modern serological testing methods used to identify blood borne pathogens. The ontologically diverse nature of both hetero- and homo- sexual behaviour is discussed, with reference to the latest HIV statistics in Ireland. Countries that have revised and shortened their lifetime MSM deferral periods are considered, as are retrospective studies of the implications these changes have had on blood supply. Finally, recommendations are given for alterations to the current screening system that could be made without compromising the safety and integrity of the blood supply.

**INTRODUCTION**

A troublesome past can cast a long shadow over any organisation, but especially one whose sole purpose is the health of a nation. The Irish Blood Transfusion Service (IBTS) (formerly the Blood Transfusion Service Board) employs a rigorous screening policy of potential blood donors. Aside from the obvious paramount duty to maintain the safety of blood product recipients, the screening policies adopted by the IBTS embody the relics of unfortunate past incidents at the organisation. Specifically, two contamination scandals which were described at the time as “the worst ... in the history of the State” still cast a shadow over two decades later.

The first of these incidents occurred during the 1970s and involved the infection of over 1000 women with Hepatitis C through contaminated anti-D blood products. Anti-D immunoglobulin derived from human plasma is typically given prophylactically to Rh negative mothers pregnant with Rh positive babies. In such situations, anti- or intra-partum mixing of maternal and foetal blood could trigger an immune response in the mother resulting in significant complications in later pregnancies. Anti-D immunoglobulin reacts with and neutralises any foetal red blood cells that enter the maternal circulation, before the mother’s immune system is triggered and sensitised. Even at the time, guidelines advised that individuals who had received a transfusion within the preceding six months were not eligible to donate. Unfortunately, a supply shortage caused these guidelines to be disregarded and plasma was obtained from donors who were concurrently undergoing plasma exchange therapy. Hepatitis C (known then as Hepatitis Non-A Non-B) ultimately entered the Anti-D blood product supply, infecting hundreds of recipients.

The second incident coincided with the emergence of HIV/AIDS and involved the supply of HIV-contaminated blood plasma concentrates to Irish haemophilia patients. Concentrates are so called as they are compiled using plasma obtained from thousands of donors. This pooling of donations greatly increased the risk posed to recipients as an entire batch could be contaminated by a single donation. In 1974, the Irish Department of Health granted a licence to American pharmaceutical company Travenol for the distribution of their concentrate product ‘Hemofil’. The provision of a financial incentive for blood donations was at the time a common practice in the United States. The practice has since been abandoned for a number of reasons including the emergence of research suggesting that such remuneration attracted donors from high-risk populations (e.g. intravenous drug users). In addition, financial incentive meant certain donors were less inclined to be entirely truthful when completing screening surveys in order to avoid rejection. In this instance, HIV-infected concentrates were imported and distributed among Irish haemophiliac individuals.

The subsequent fallout from these events damaged the reputation of the IBTS enormously. It is therefore unsurprising that the organisation is reluctant to revive its lifetime deferral policy of MSM blood donation.

**HIV/AIDS, THE MSM BLOOD BAN & CURRENT SEROLOGICAL TESTING**

Deferral periods - defined restriction periods from the last time that an individual engaged in a risk behaviour to the time they regain eligibility to donate - are now common at blood transfusion agencies across the globe. The theory behind such deferral periods is that any donors infected with a blood-borne pathogen will have seroconverted by the time they are again eligible to donate. This significantly reduces the likelihood of donating within a “window period” between exposure and seroconversion. In 1985, as the full extent of the Acquired ImmunoDeficiency Syndrome (AIDS) epidemic was becoming apparent, the United States Food and Drug Administration (FDA) introduced an indefinite deferral period, i.e. lifetime exclusion on MSM blood donations. Most other countries promptly followed suit. Given that so little was known about HIV (other than it predominantly affected sexually active gay men) and there were no available tests to accurately ascertain HIV status, most will agree this was an appropriate course of action.

The ban was introduced in 1985 as a temporary measure yet three decades later it is still in place in many countries. Today in Ireland, any man who has ever had sex with a man is excluded from blood donation for life.

In the years that have passed since these bans were introduced, serological testing has advanced exponentially. Highly sensitive assays are used to detect the presence of various known blood-borne viruses and pathogens including HIV, Hepatitis B, Hepatitis C, Human T-lymphotropic virus and syphilis. In the case of HIV, extremely sensitive combination antigen/antibody ELISA assays can detect the virus as early as a week following exposure. Where infection is suspected, the Western blot test - considered the gold standard in HIV confirmatory testing -
identifies specific proteins associated with the Human Immunodeficiency retrovirus which can be detected in blood as early as three weeks following initial exposure. Of most relevance to this paper is the fact that over 99% of those infected with HIV will demonstrate a seropositive test result within three months.6 In light of these advancements many now question indefinite deferral policies - indeed even the American Association of Blood Banks (AABB) have described them as “medically and scientifically unwarranted”.7

There is no denying that HIV/AIDS continues to affect a disproportionate number of MSM in Ireland compared to their heterosexual counterparts, statistics which are mirrored in most other Western countries. According to the latest figures released by the National Health Protection Surveillance Centre, MSM accounted for the highest proportion of new HIV diagnoses in 2013 as it has done every year since 2009. 131 of the total number of new diagnoses made, 131 were heterosexual while 131 were MSM.8

**RISK BEHAVIOUR & THE DIVERSITY OF SEXUAL PRACTICE**

Speaking on their own behalf as well as on behalf of the the American Red Cross, the AABB agree that to differentiate between disease transmission via male-male sexual activity and male-female activity on scientific grounds is irrational.7 At the crux of this stance lies the fact that, among both hetero- and homo- sexual people, patterns of sexual activity are ontologically complex and diverse.9

A major criticism of blanket bars and homogenised risk groups are that they commit an ecological fallacy - that is, the drawing of conclusions about individual behaviour based on a group as a whole. Failure to disaggregate broad population-level risk groups means that the reported risk they embody is obscured relative to population level statistics. It is incorrect to infer that all men who have sex with men engage in high risk behaviour just as it is incorrect to assume that all heterosexual activity is low risk.5,10

Studies on risk rarely take into account MSM in monogamous relationships or those who engage in low risk activity and/or regularly use condoms. Examination of data reviewed by the Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO) reveals that half of MSM surveyed had no penetrative experience and almost 45% had only ever had one sexual partner.11 Critics also point out that research often compares MSM and heterosexual males despite the fact heterosexual females are biologically at greater risk of infection from unprotected sex. Nevertheless, lifetime deferral persists: in the words of one member of the US FDA Blood Products Advisory Committee (BPAC), although it is “non-specific…(and…) overreclusive…it works… because it captures the high-risk subset”12

According to the IBTS website, those donors who exhibit “a particularly high risk of carrying blood-borne viruses” are asked not to donate blood. They further state that the total MSM exclusion policy is “not based on sexuality or orientation, only specific actions.” If exclusion policies are (as the IBTS claim) truly based on specific high-risk actions, then their donor screening policy should reflect this: at present, it does not. Any man who has ever had sex with another man is excluded from donation for life even if both are negative for HIV and despite their sexual history or the potential risk of their sexual practices. In contrast, the deferral period for heterosexual donors who have knowingly engaged in unprotected sex with a person with HIV or hepatitis is only 12 months. Comparing the zero tolerance approach to MSM donors to that applied to risk-associated heterosexual behaviours, the difference is arguably inequitable.13

Risk associated with heterosexual behaviour is rarely acknowledged or scrutinised in studies despite the fact that, as epidemiologist Geoffrey Rose stated, “a large number of people at small risk may give rise to more cases than a small number of people at high risk.”13,14 For example, examination of a study by Sanchez et al. involving over 25,168 male American blood donors, shows that while approximately 17 contaminated donations could be attributed to MSM who did not defer appropriately (accounting for 6% of MSM donors), the number attributable to heterosexual donors was approximately 418 (approximately 1.7% of heterosexual male donors).15 The percentage of MSM is evidently higher, however that of heterosexual donors is significant. Despite the high number of contaminated heterosexual samples, the MSM figures dominate policy discussion. In addition, there is concern that indefinite exclusion policies perpetuate the impression in the public psyche that HIV is a selectively “gay” disease, and that heterosexuals are somehow at lower risk of acquiring a sexually transmitted infection.16

**DEFERRAL POLICIES ABROAD**

When considering viable alternatives to the lifetime deferral policy, it is useful to look to other countries where deferral periods have already been revised. Leiss et al. highlight two benefits that such a policy change might bring about. First, revised deferral would lead to an increased pool of future donors. This pool would consist of newly eligible MSM donors and those who currently decline to donate due to disagreement with the perceived discriminatory nature of the current MSM lifetime ban. Second, there would be a social benefit in terms of a reduction of the stigmatising association of HIV and homosexuality.17 Various studies also suggest that revision of deferral policies can reduce the risk of an infected donation entering the blood supply due to improved donor compliance.18

Italy has one of the shortest deferral periods exercised in the world excluding countries where no deferral period is in place. For over a decade Italy has used extensive assessment of donor sexual history (both heterosexual and homosexual) to ascertain risk and suitability.19 Those demonstrating ‘risk’ behaviours (e.g. sex with a HIV-positive individual) are deferred for four months following which they are reassessed for eligibility. Lifetime exclusion only applies to those who have engaged in high-risk behaviour such as intravenous drug use, sexual activity with sex workers, or sex with multiple HIV positive partners. Crucially, studies have shown that the absence of an MSM ban “has not led to a disproportionate increase in HIV-seropositive MSM” donors.20

Twelve-month MSM donation deferral is now practised in various countries including Australia, the United Kingdom (excl. N. Ireland), Sweden, Czech Republic and Hungary.21 Lifetime deferral was reduced to one year in the United Kingdom (excl. N. Ireland) following recommendations from an advisory committee on the Safety of Blood, Tissues and Organs (SaBTO).22 SaBTO concluded that the levels of risk associated with indefinite deferral and with 12-month deferral, were no different. Recent studies in Australia, where one-year MSM deferral has been in place since 1997, have found no evidence of increase in HIV transmission following the implementation of this policy.23 Here, assessment takes into account not only MSM but heterosexual risk behaviour including males who have sex with prostitutes or intravenous drug users, and females who have sex with males from high-risk countries.24

Despite the number of countries adopting the policy, the available literature does not unanimously support 12 month deferral as a risk-free option. Although no exact figures are referenced, Leiss et al., (2008) postulate a “low incremental risk” associated with 12-month deferral policies that they deem an unacceptable increased risk to the safety of blood recipients.25 They cite work by Germaine et al. which suggested an increase as high as 8% in infected donations should a one-year deferral policy be implemented.22

Beyond 12-month policies, five-year deferral periods are another option in place in various countries. Leiss et al., who expressed reservations about a 12-month deferral, note that there is no evidence of risk associated with a five-year deferral period, and thus this alternative passes “the risk hurdle”. Subsequent to the publication of this paper, a five-year deferral period was introduced in Canada.26 Sanchez et al., also note that the risk posed by a male with 5-year deferral from MSM activity was comparable to that of a male who had never engaged in such activity.25,27 New Zealand also operates a five-year deferral policy for MSM donors.1

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The current prospective donor questionnaire could also be revised to facilitate a more comprehensive screen of high-risk donors based on sexual behaviour as opposed to orientation. In a paper regarding the efficacy of excluding population-based risk groups, Kesby and Sothern advocate practice-based exclusion. They point out that the risk of disease transmission varies depending on three variables: the likelihood that an individual’s sexual partner is infected; the nature of sexual activity engaged in; and the frequency of exposure. An accurate risk screen should therefore aim to establish such information from all prospective donors regardless of sexual orientation. Such a revision could only enhance the identification of risk donors, ultimately buttressing the safety of the blood supply.

**RECOMMENDATIONS/CONCLUSION**

Revocation or revision of policy in jurisdictions with a history of tragedy is especially understandable that the IBTS is reluctant to consider alteration of its current donor restrictions. The aforementioned research and examples of policies abroad suggests that changes could be introduced to the IBTS screening process without compromising the safety and integrity of the blood supply.

First, the IBTS could consider shortening its MSM deferral period to five years. While opinions regarding 12-month deferral remain divided, research demonstrates a consensus that five-year deferral policies have no impact on risk. The lack of substantial evidence of increased risk associated with such a change calls into question whether it is necessary or appropriate to continue such an exclusionary policy, regardless of the state of the blood supply or financial feasibility. As Leiss and his colleagues (2008) eloquently state: “there are very few rules involving noncriminal personal choices in our society that carry, as a penalty for violating them, a lifetime ban on being able to perform one of the noblest acts, namely, donating blood freely and without recompense.”

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**Author’s note:** In January 2015, Irish Minister for Health Leo Varadkar announced that he had requested a review of the deferral policies employed by the Irish Blood Transfusion Service. Minister Varadkar stated that he favours a one-year deferral policy but that any changes will be based on scientific evidence.
Food Poverty and Policy in Ireland: A Review of the Literature

Written by Diarmuid D Sugrue

Edited by Prof. Ivan Perry, MD, PhD, Professor of Public Health & Head of the Department of Epidemiology & Public Health, University College Cork

Keywords: Food Poverty, Ireland, Health and Behaviour in School-aged Children (HBSC), Diet, Policy, Public Health

UCD School of Medicine and Medical Science, University College Dublin, Belfield, Dublin 4, Ireland
Food poverty has emerged as a social policy issue in Ireland, Northern Ireland and the rest of the world. The concept of food poverty is defined as “the inability to afford or have reasonable access to food which provides a healthy diet”.

It found that 10% of the Irish population was living in food poverty, defined as those who had experienced at least one of the first three factors in the preceding month.

This figure was higher for particular groups such as low income earners, with almost 1 in 4 one-parent families and unemployed persons in food poverty.

However, food poverty in Ireland has not been included in national surveys. There is currently no coordinated policy in Ireland to guide initiatives which might address social inequality in dietary behaviour. Given the changed economic landscape of the last 7 years, it is apparent that the official figures for food poverty in Ireland must be reviewed.

The creation and acceptance of a standardised measure of food poverty is paramount in order to comprehensively understand the scale of the issue. An updated and coordinated all-island policy is urgently needed to address social exclusion. Using three basic deprivation indicators from SILC, and adding a fourth, a definition of food poverty was constructed. The indicators were:

- Not being able to afford a meal containing meat or vegetarian equivalent every second day
- Not being able to afford a roast dinner once a week
- Missing at least one substantial meal over a two-week period due to lack of money
- Inability to have family or friends for a meal or drink once a month

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The purpose of this review is to heighten awareness of food poverty as a public health issue in Ireland, and to critique what is being done to curb it. Part A quantifies food poverty in Ireland, the effect it has on personal health and the implications for our health system. Part B examines national policies aimed at alleviating food poverty. The review focuses primarily on research conducted by government, public health institutes, international bodies, non-governmental organisations (NGOs) and charities.

**PART A: FOOD POVERTY IN IRELAND**

1. **FOOD POVERTY INDICATOR**

Although never measured directly in Ireland, Carney and Malte constructed a food poverty indicator based on Central Statistics Office (CSO) figures contained in the annual Survey on Income and Living Conditions (SILC) between 2004 and 2010. This study was the first of its kind in Ireland, attempting to distinguish food poverty from other types of poverty, such as material deprivation, fuel poverty, financial and social exclusion. Using three basic deprivation indicators from SILC, and adding a fourth, a definition of food poverty was constructed. The indicators were:

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Food Poverty among schoolchildren in Ireland - HSBC

3. SOCIOECONOMIC VARIATION

Population-based studies worldwide have repeatedly shown that people from lower socioeconomic groups have less healthy dietary habits.\(^7\) \(^8\) The Survey on Lifestyle and Attitude to Nutrition (SLÁN) 2007 noted that consumption of foodstuffs advocated by healthcare professionals as being health promoting (such as low-fat milk, fruit, and white meat) is lower among the lowest socio-economic quintiles. Conversely, consumption of fried foods at least twice a week was higher in every age group for children reporting that they went to school primarily by affordability.\(^9\) Factors contributing to this include affordability, accessibility, availability and awareness. Although SLÁN pinpointed education as the dominant socio-economic factor by which nutrients vary, Friel and Conlon concluded that socially disadvantaged groups display awareness of what constitutes healthy eating, yet are constrained from adopting this knowledge on a population-wide basis. This is certainly a persuasive and valuable document.\(^2\) (PP4)\(^1\)

Self-reported food deprivation was higher in the lowest quintiles of income and social class in each of the studies. Thus, there is a definite trend in nutritional discrepancies across the Irish population. Carney and Malte composed their index based on three food deprivation items as this was considered more appropriate than using each item individually, and more accurate as people may restrict spending in one area but may not in another.\(^6\) (PP24) The specificity of the "unable to afford family and friends for a meal or drink" item was low, given how it augmented measurements. However, exclusion of this item prevented measurement of the social participatory aspect of food poverty.

The available data on food poverty in Ireland are now dated – Carney and Malte’s and HBSC’s figures both come from 2010. Likewise, although important studies, the figures contained in Friel and Conlon (2004) for the Republic of Ireland and Purdy et al (2006)\(^11\) for Northern Ireland are too dated so as to be accurate given the economic changes of the last decade. As previously mentioned, no direct population-wide analysis of food poverty has ever been carried out in Ireland - like previous studies, Carney and Malte used secondary data analysis, not designed to specifically answer their research questions. This limits the accuracy of the measures used. SILC does not measure access to food, nor the nutritional quality of that which is affordable.

Vulnerable groups such as the homeless, asylum seekers, Travellers and those living in institutions were excluded from SILC 2010 and therefore the food poverty indicator 2012, as SILC is a private household survey. The Department of Social Protection commented at the time that this “limited” the findings. Carney and Malte also failed to indicate geographical variations in food inequalities across the country. With Friel and Conlon having identified these issues eight years previously, it seems there have been major, and as yet unrectified, structural problems in how food inequality in the Irish population has been quantified over last 10 years.

HBSC is a school-based survey with data collected through self-completion questionnaires administered for Ireland’s fifth instalment, and these data will offer a more up to date picture when they are published in 2015.

Carney and Malte provide the most comprehensive guide for assessing food poverty in Ireland, and it is certainly a persuasive and valuable document. However, like Friel and Conlon and Purdy et al (whose figures focused primarily on Household Budget Surveys), the indicators for food poverty were based on affordability of food. The study then could only allude to the more composite picture of food poverty incorporating accessibility, education, location and social exclusions. Unfortunately, this food poverty indicator stands alone in an Irish context; without detracting from its importance, it is therefore difficult to critique in relation to anything else.


EFFECT ON HEALTH

The role of diet in chronic diseases such as hypertension, coronary heart disease, diabetes, stroke, obesity, and certain cancers has been well documented since Ancel Keys “Seven Countries Study” was first published in 1963.14 There has been much debate in the interim as to what constitutes the optimal diet; nonetheless there is a general consensus that fresh fruits and vegetables, whole grains, lean meat and fish are preferable to processed food high in salt, added sugar and saturated/trans-fats.

Figure 3

Percentage self-reported as obese in each social class

Source
SLÁN 2007: Survey of Lifestyle, Attitudes & Nutrition in Ireland

Growing up in Ireland (2009) echoed this; 19% of boys and 18% of girls from professional households were overweight/obese, while 29% of boys and 38% of girls from semi- and unskilled social-class households were overweight/obese.14 International data reaffirm that the highest rates of obesity are found among minorities and the working poor.17,18 Given that food poverty necessitates the consumption of low cost (and therefore) energy dense foods high in fats and refined sugars, and these foods increase the risk of obesity and cardiovascular disease, it is safe to say that food poverty is a major contributing factor to the high rates of obesity seen among lower socio-economic groups in Ireland. Thus, obesity is a socio-economic phenomenon with food poverty as a major risk factor.

Food Poverty and Policy in Ireland: A Review of the Literature

The charity sector has taken on much of the burden of alleviating food poverty. Focus Ireland, Crossecare and The Society of St. Vincent de Paul (SVP) are all involved in the direct provision of food, with SVP alone spending €22 million on food and cash assistance in 2011.22 New charities such as Foodcloud use mobile apps to connect businesses with surplus food to charities who can distribute it.

2. STATE PROVISION

Food cost, welfare, and direct provision are all intervention targets. Employment is the central theme of poverty eradication policy in Ireland. However, with recent criticism that minimum wage falls below a “living wage”, it seems that employment alone does not prevent poverty. The benchmarking of welfare payments to average industrial earnings called for by Friel and Conlon and other commentators is idealistic and unlikely given the country’s finances. In terms of food cost, the reform of EU Common Agricultural Policy (CAP) under Irish Presidency in 2013 may lead to increased competitiveness and reduced cost to the consumer. The removal of restrictions on production volume of dairy products will reduce prices, whilst potentially driving other farmers towards vegetable or timber farming. Although there is still an issue of food waste, €3.5 billion has been allocated to the Fund for European Aid to the Most Deprived for 2014-2020, to redistribute surplus food.24

Direct provision through the Schools Meals Programme operated by the DSP provides food services for disadvantaged children. Currently, this is implemented on a case-by-case basis, targeting those most in need, incorporating over 60,000 children. The long-term objective is that all school-going children should have access to meals in their school setting. Nutrition guidelines are in place for each meal with breakfast, lunch and snacks aimed at providing 25%, 33%, and 10% of recommended daily allowance respectively.24 Since 2007, the Food Dudes Healthy Eating Programme has been rolled out in primary schools across Ireland to encourage children to eat more fruit and vegetables. This has now been augmented by the EU School Fruit scheme, and the Department of Agriculture aims to have run the programme in 96.8% of all primary schools by the end of the 2014/15 school year.24
CRITICAL ANALYSIS

While the DFPA project was promising, it was carried out in a small area and there was no follow up of participants. Although there was positive feedback from those who participated in the workshops, the level of understanding of term “healthy eating” actually decreased during the intervention period, and DFPA had no impact on the percentage of adults who were overweight or obese. 23,24,25 Comparatively, HFA has no data about how the community-based projects it runs have alleviated food poverty. Although charity may be beneficial, it is supportive not curative, and should not be considered a sustainable policy.

Resourcing the School Meal Programme has many potential benefits. Not only does this ensure that children receive a balanced food intake, but it can educate them about what comprises a nutritious meal. A move towards universal provision ensures that all children benefit from enhanced nutrition and meals. A move towards universal provision ensures that all children benefit from enhanced nutrition and meals.

Health Literacy” is a concept which carries cache undervalued in determining the food economy and undervalued in determining the food economy and environment pertaining to reducing the cost of healthy eating. However, Hawkes et al. (2014) warned that “health literacy” is a concept which carries caché and undervalued in determining the food economy and environment pertaining to reducing the cost of healthy eating.

CONCLUSION

The lead editorial in The Lancet in May 2014 warned how food poverty “lay at the heart of appalling health.” 26 The same issue contained an open letter addressed to UK Prime Minister David Cameron signed by 170 members of the United Kingdom Faculty of Public Health, warning of the looming health crisis in poverty, and for an independent advisory board to monitor nutrition and hunger status. Given the analogous crisis in Ireland, similar initiatives are required here. Firstly, it is evident that the creation and acceptance of a standardised measure of food poverty that includes all of society is paramount in order to comprehensively understand the scale of the issue. Secondly, an updated and coordinated all-island policy is urgently needed, coordinating numerous sectors: public health, social work, charity, education and local government. Finally, this policy should not merely focus on education and community work, but on challenging industry to improve our food environment. With the impending tsunami of chronic disease caused by poor nutrition, resolving food poverty should be central to health policy in Ireland.

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The Use of Aspirin for Primary Prevention of Cardiovascular Disease: Review of Literature and Sample Evidence of Common Practice in Ireland

Written by John Travers
Edited by Dr. Helen Gallagher PhD, Senior Lecturer, School of Medicine and Medical Science, University College Dublin

UCD School of Medicine and Medical Science, University College Dublin, Belfield, Dublin 4, Ireland

Key words: Aspirin, Cardiovascular Disease, Primary Prevention, Bleeding Risk, GP Practice, Audit, Preventative Medicine
**ABSTRACT**

The use of aspirin and broader anti-platelet therapy is well established for secondary prevention of cardiovascular (CV) events such as myocardial infarction, stroke or transient ischaemic attacks. However, there is significant and growing evidence in the literature to conclude that the net benefits from taking aspirin for primary prevention (an unlicensed indication) are minimal and are counterbalanced by harms such as gastrointestinal and extra-cranial bleeding.

Audits of GP practices suggest that prescription of aspirin for primary prevention is in fact common, despite the risks. Almost a fifth of patients taking aspirin in two practices in Dublin and Cork use the drug for primary prevention.

The risks and potentially fatal complications of bleeding should be carefully considered and discussed with patients when prescribing aspirin for secondary prevention of CV events and, on the basis of the most recent evidence, aspirin should not be routinely prescribed for primary prevention. A broader preventative approach such as addressing modifiable risk factors with patients at planned health checks can instead yield better overall outcomes. Guidelines on the use of aspirin in prevention of CV events should be updated to reflect the bleeding risks outlined in recent research.

**INTRODUCTION**

Aspirin and its precursors have played a role in healthcare for millennia. It is said that Hippocrates offered pregnant women willow leaves in order to ease labour pains c400BC. The active ingredient of this traditional analgesic, salicylic acid, was first extracted from willow in the 19th century. Aspirin was synthesised by adding an acetyl group to salicylic acid to make it more tolerable for taking orally. Although one of the earliest drugs developed, aspirin is today one of the most commonly taken. Its use has expanded from pain relief to helping in the management of conditions such as cardiovascular disease (CVD), colon cancer and dementia.

Aspirin irreversibly inhibits cyclooxygenase (COX) enzymes that produce the prostanoid mediators of inflammation, resulting in anti-inflammatory, analgesic and antipyretic effects. COX inhibition also blocks aggregation of platelets. This reduces the risk of myocardial infarction (MI) or stroke due to thrombus formation following atherosclerotic plaque rupture.

The mechanism by which platelet aggregation is blocked begins with COX enzyme acetylation. There is a consequent reduction of thromboxane A2 (TXA2) synthesis in platelets and prostaglandin I2 (PGI2) synthesis in vascular endothelium. TXA2 promotes platelet aggregation by up-regulating integrin surface receptors that cross-link other platelets with fibrinogen to stabilize a platelet plug, while PGI2 inhibits aggregation by disrupting arachidonic acid induced adhesion. TXA2 can only be replenished by new platelets that develop after about 10 days. However, PGI2 can be renewed much sooner by vascular endothelium. Therefore, the overall balance of activity is shifted against platelet aggregation. A low dose of aspirin is efficacious due to the irreversibility of COX enzyme inhibition and an accumulation effect over a few days. Some 50% of TXA2 is suppressed with a first dose of aspirin. A second dose increases suppression to 90% and full suppression can be maintained by a regular low dose.

The beneficial use of aspirin as an anti-platelet therapy is widely accepted in secondary prevention of CV events. However, the anti-platelet effect also increases the risk of bleeding. For patients who have not yet experienced a CV event, the benefits of the anti-platelet effect in primary prevention of CV events do not outweigh the bleeding risks associated with aspirin.

**STUDIES ON EFFECTIVENESS OF ASPIRIN USE IN PRIMARY PREVENTION**

Multiple published studies consistently show that the use of low dose aspirin for primary prevention of CV events does not provide net benefit to patients. Perhaps the most comprehensive of these studies in recent years was the Antithrombotic Trialists’ Collaboration in 2009. Researchers assessed trials of aspirin use in 95,000 individuals in primary prevention and 17,000 individuals in secondary prevention. They undertook collaborative meta-analyses of serious vascular events (i.e., MI, stroke, vascular death) as well as major bleeds. They found that aspirin allocation for primary prevention yielded a 12% reduction in serious vascular events (mainly due to a reduction of just under a fifth of non-fatal MI) though had no significant net effect on stroke and no significant difference in vascular mortality was found. However, they found that aspirin use increased major gastrointestinal and extra-cranial bleeds by just over 40%. The study strongly supports the view that aspirin does not achieve net benefit in primary prevention as the reduction in CV events is offset by an increase in major bleeds.

The point is further underlined by researchers at the Drugs and Therapeutics Bulletin. They reviewed several meta-analyses in 2009 and found that the benefits of MI or stroke prevention do not outweigh the increased risk of gastrointestinal bleeding. They proposed that the use of low dose aspirin for primary prevention of MI and stroke in patients with no CVD had no effect on mortality and should not be routinely initiated, even in those with elevated blood pressure or diabetes. Furthermore, they suggested that people currently on aspirin for primary prevention should review with their doctor whether to continue taking the drug.
In fact, findings that highlight how bleeding risks counterbalance benefits of aspirin use in primary prevention have been echoed in compelling results from several other international studies for several decades. For instance, a randomised trial of prophylactic daily aspirin in 5,139 British male doctors with no known CVD between 1978 and 1984 found no clear indication of a decrease in mortality from CV events. A similar, contemporaneous US study found no reduction in mortality from all CV causes in 22,071 healthy men treated with aspirin or placebo in a randomized trial. The study identified that aspirin helped reduce the risk of MI by 44% but that moderate-severe and fatal haemorrhagic stroke risk was more than doubled.

More recent studies such as the ‘Hypertension Optimal Treatment’ (HOT) trial further strengthen the argument against the use of aspirin for primary prevention. Aspirin use had no significant effect on cerebral vascular accidents or CV mortality in trials conducted with 18,790 patients for primary prevention across 26 countries. While the HOT study recorded a reduction in MI, it also recorded an increase in major non-fatal bleeds and minor bleeds. Furthermore, a 2005 Women's Health Study with a randomized trial of 39,876 healthy women treated with aspirin or placebo failed to show any significant improvement in the primary prevention of non-fatal MI, stroke or death from CVD. Some guidelines recommend the use of low dose aspirin in patients with type 1 or 2 diabetes for primary prevention of CV events. However, the Prevention of Progression of Arterial Disease and Diabetes (POPADAD) and the Japanese Primary Prevention of Atherosclerosis with Aspirin for Diabetes (JPAD) trials both concluded in 2008 that there is no evidence to support the use of aspirin in primary prevention in patients with type 1 or 2 diabetes. In fact, POPADAD found that deaths from coronary heart disease or stroke among were higher among aspirin users compared to non-aspirin users (6.7% vs 5.5%).

A random sampling study of 88,698 aspirin users in Taiwan published in 2015 showed that the bleeding risk of regularly taken low dose aspirin cancelled any contribution to preventing major vascular disease. Patients who used low dose aspirin occasionally (less than 20% of the time) had better health outcomes than those who used it regularly (more than 80% of the time). A BMJ editorial on the use of aspirin in prevention of cardiovascular events reported that studies have consistently failed to demonstrate net benefits for primary prevention in patients without CVD. It cited a review by the US Food and Drug Administration (FDA) of the proposed labelling of aspirin for primary prevention, which evaluated five primary prevention trials, none of which showed net benefits from aspirin use in primary prevention. These trials also failed to show a benefit in patients with diabetes or a Framingham risk score greater than 8-10% over 10 years.

All of the literature reviewed points to a consistent conclusion: any benefits of aspirin use for primary prevention of CV events are counterbalanced by potentially fatal bleeding risks.

Some guidelines recommend the use of low dose aspirin in patients with type 1 or 2 diabetes for primary prevention of CV events. However, the Prevention of Progression of Arterial Disease and Diabetes (PAPAD) and the Japanese Primary Prevention of Atherosclerosis with Aspirin for Diabetes (JPAD) trials both concluded in 2008 that there is no evidence to support the use of aspirin in primary prevention in patients with type 1 or 2 diabetes. In fact, PAPAD found that deaths from coronary heart disease or stroke among were higher among aspirin users compared to non-aspirin users (6.7% vs 5.5%).

In the light of the most recent research (specifically the Drugs and Therapeutics Bulletin research described above), the Irish College of General Practitioners confirmed that aspirin should only be taken on the advice of a GP or healthcare professional. The National Medicines Information Centre at St. James’s Hospital, Dublin, outlined that aspirin mono-therapy is no longer recommended for certain primary prevention such as atrial fibrillation related thromboembolic events, due to the risk of bleeding as well as the observation that the anti-thrombotic effect of aspirin appears to lessen with age. The ESC also updated its guidelines based on recent research to state that aspirin is not recommended in individuals with cardiovascular or cerebrovascular disease due to the increased risk of major bleeding. It appears that the guidelines are slowly changing to reflect the evidence on risks of aspirin use in primary prevention.

### RELEVANT GUIDELINES

There are several UK and European guidelines that describe aspirin use in patients for primary prevention of CVD. However, it should be noted that these guidelines were published between 2005 and 2008, prior to the most recent research, which highlights the risks of aspirin in primary prevention.

Three key guidelines are as follows:

- The Joint British Societies issued guidance in 2005, recommending aspirin 75mg daily for people over 55 years with a total CVD 10 year risk above 20%, as well as for people with diabetes aged over 50 (or younger if they had diabetes for more than 10 years or have been receiving treatment for hypertension), once blood pressure has been controlled to 150/90 mmHg or less.

- The Fourth Joint Task Force of the European Society of Cardiology (ESC) guidelines recommended in 2007 that patients take aspirin 75mg daily if their 10-year risk of CVD mortality is over 10% and blood pressure is less than 140/90 mmHg.

- The National Institute for Health and Clinical Excellence (NICE) published a guideline in 2008, recommending aspirin 75mg daily for people over 50 years with type 2 diabetes if their blood pressure is below 145/90 mmHg.

### SAMPLE EVIDENCE OF COMMON USE OF ASPIRIN FOR PRIMARY PREVENTION

An audit was conducted at the Dun Laoghaire Surgery, Co. Dublin, as part of this review to identify patients who were taking aspirin for primary prevention that did not meet any of the above guidelines.

All patients at the practice that had been taking aspirin (75mg daily) in the 24 months prior to July 1, 2013, were identified by a medications search of electronic records. This amounted to 385 patients. 19 of these had either passed away or left the practice in the interim. The histories of each of the remaining 366 patients were reviewed. All those who had experienced a MI, CVA or TIA and therefore were being managed for secondary prevention were excluded. Furthermore, patients with a high CVD or CV event risk - for instance, those diagnosed with peripheral vascular disease, had demonstrable CV symptoms such as unstable angina or intermittent claudication or who had stents or prosthetic valves in place - were also excluded.

70 patients that had not experienced a CV event and did not fall into the CVD high risk category described above were taking aspirin for primary prevention. These patients had conditions such as controlled hypertension, ‘once-off’ chest pain or had a family history of CV events. These patients amounted to 19% of all current patients taking aspirin for secondary or primary prevention. The 70 patients ranged in age from 35 to 91 years. The median age was 74.5 years, while the average age was 72.4 years.
An audit conducted in the Broadline Family Practice, Blackpool, Cork, in 2011 and 2012 and published in 2013 found results comparable with the Dun Laoghaire audit. 333 patients were identified to be using aspirin “inappropriately”. The patients had no CVD and their 10-year CVD risk was low. Their use of aspirin introduced risks of gastrointestinal bleeding and haemorrhagic stroke that outweighed benefits in primary prevention.23

Inappropriate use of aspirin for primary prevention does not appear to be an issue unique to Ireland. A study published in 2015 reviewed aspirin use by 68,808 patients in 119 practices across the US and determined that 11.6% of these patients were using aspirin “inappropriately”. The patients had no CVD and their 10-year CVD risk was low. Their use of aspirin introduced risks of gastrointestinal bleeding and haemorrhagic stroke that outweighed benefits in primary prevention.24

How might we broaden preventative medicine in Irish GP practices to address CVD risk factors? Interestingly, financial incentives do not appear to help. Only one out of eight financial incentive programmes implemented between 1966 and 2002 in English speaking countries motivated doctors to provide more preventative care.25

The answer may lie instead in introducing planned health checks for all patients over the age of 45. A randomised controlled trial of 1,507 Danish patients showed that the number of patients at elevated cardiovascular risk was halved as a result of biannual health screenings in family practices over five years.26 The approach is similar to the ‘Managed Care’ philosophy implemented by Kaiser Healthcare in the US, which offers five annual planned health checks to patients over 45, reducing the incidence of acute care emergencies, decreasing the days spent in a hospital bed and improving overall outcomes.

Health check activities could be shared between practice nurses and doctors to help manage limited time resources. This form of preventative medicine, where patients and healthcare professionals actively collaborate on managing smoking, alcohol, diet and exercise would lead to improved health outcomes, lower healthcare costs and help avoid unnecessary prescription of aspirin and consequent bleeding risks in primary prevention.

The November 2014 conference of the Irish National Institute for Preventive Cardiology (NIPC) highlighted how 50% of over 50s are overweight or obese, 30-50% have elevated blood pressure, 34% have low rates of exercise, 20% smoke and 16% report alcohol problems.27 Speakers at the NIPC conference also outlined how CVD was the single largest cause of death in Ireland and that more than 50% of reductions in CVD relate to risk factor changes.28 It would appear there is much room for improvement in reducing risk factors for CVD events that can make a major difference to the health of patients.
CONCLUSION

Evidence in the literature points to significant risks of bleeding associated with aspirin use that counterbalance benefits in primary prevention of CV events. Despite this, fact-based audits highlight that use of aspirin for primary prevention of CVD and CV events is common. The fact that UK and European guidelines do not reflect the most recent research on the issue may contribute to this. This paper offers three suggestions to address the issues of aspirin use in primary prevention in light of the above findings. Firstly, doctors should engage with patients who take aspirin for primary prevention to review the full benefits and risks. Secondly, it is worthwhile for doctors and patients to invest time in identifying and managing modifiable risks for CVD and conduct regular, planned health checks. Lastly, relevant guidelines should be updated to reflect recent research on the bleeding risks of using aspirin in the prevention of CVD and CV events. These findings and suggested actions could be communicated effectively through the medium of the National Institute for Preventative Cardiology Alliance, which brings together healthcare providers, institutions and society in preventive action. Putting these suggestions into practice would improve overall healthcare and patient outcomes.

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A Day in the Life...
of an Intern in Ireland

Written by
Maeve Montague
Featuring
Dr. Ken Fitzpatrick
You made it through the Leaving Cert, the years spent in the lecture theatres of the Health Sciences Building on college campus, and then it is time to don the white coat as the clinical years begin. But what happens next? The life of a medical intern can be hard to understand past the headlines dominating the media - long hours, fatigue, a fluctuating payscale - so what is the reality?

According to Dr. Ken Fitzpatrick, "It’s not so bad. You’ll enjoy it - really". A current surgical intern at St. Vincent’s University Hospital, the experience is not how Ken initially expected. "During your clinical years you don’t really have the chance to see the interns at work, so when you start it can seem like you’re in at the deep-end at first. But I can honestly say I learned more in my first month working, than the entire previous four years of graduate medical school".

After applying competitively for schemes following graduation, interns in Ireland find themselves across the country, becoming the newest team member, and the one responsible for managing the patient list. A list of all those in the care of your team, it is "the most important thing for an intern. It can change drastically, across the country, becoming the newest team member, and the one responsible for managing the patient list." You need to have the source of all information – from what tests and imaging have been taken, to those that are still outstanding – so what is the reality?

In times of a greater workload, epitomised by the sounds of a never-ending bleeper, it is the supportive network of the team that allows interns to work without feeling too overwhelmed. "There can be a feeling of guilt when you call someone, but it’s specified that no-one minds. The Senior House Officers (SHOs) are really approachable, and while there is a chain-of-command, in that Registrars prefer to be called by SHOs who are called by you (the intern), patient safety is what ultimately matters - that’s the rule".

“PATIENT SAFETY IS WHAT ULTIMATELY MATTERS - THAT’S THE RULE”

With the recent ‘24 No More’ campaign, and regular media coverage of doctors’ working hours, it might not be a surprise to learn that it is the on-call shift which most worries new interns. "The first couple of shifts were pretty terrifying - I was definitely nervous. You have this idea in your head that you’re not going to be able to deal with, what could be, a vast number of problems. But the assessments are all the same at the end of the day, so as long as you get the wheels in motion you’re keeping up with the team's expectations”.

For surgical interns on-call, it is the medical Registrar on-call who becomes their saviour. Unlike surgical Registrars, who can go home if not needed in theatre, the medical Registrar stays in the hospital and is often at the other end of the phone, willing to give advice. "You definitely feel like a student at first. Being on-call teaches you that you need to get things done. When you no longer have an SHO to turn to, you realise that you have to keep trying. This makes you learn fast and, while it might seem a lot of pressure at first, it stands to you in the long run. By the second or third on-call shift the worry fades – physical exams and taking a history followed by collecting bloods and taking cultures become part of the motion”.

During a night shift interns are ruled by 'sweeps and bleeps'. Sweeps - a list of non-urgent jobs put up by the nurses on each ward – can range from rewriting drug card indexes to placing cannulas; while bleeps are usually a call to assess a patient. Interns prioritize these duties, and while a 24-hour shift can be hard to adjust to – "it can be fun - there’s usually a great camaraderie between the two interns on-call. There’s a chance for some down-time and to order-in food – generally the work load is divided to allow each intern to take 2-3 hours of sleep at a time”.

With interns starting at 6:45am, mornings need to quickly be adjusted to - there are, however, a few silver linings. "There’s very little traffic at 6am, and always plenty of parking". Another matter is breakfast - which really does become the most important meal of the day - as being busy, while good for time passing by, can often lead to missed meals. "You never know when you’re going to be bleeped, so be prepared to take any opportunity you have to grab something".

Formal teaching continues throughout the year, with two lunchtime meetings per week, via the Dublin Academic Medical Centre (DAMC) Intern Training Program. As well as teaching, this also offers interns the opportunity to present interesting cases, and network with other interns across different schemes. Within the surgical team, there are further opportunities to learn more after morning ward rounds during the week – from a radiology meeting on Tuesday, to a Journal Club across general surgery on a Wednesday, or a research meeting on Thursday.

Though much of current media has focussed on the rising emigration of Irish doctors, Ken is more hopeful on the subject. "Irish doctors have always emigrated. I think a lot of graduates want the experience of working in a different country, but most intend to return with new skills". He also feels that the issue of the European Working Time Directive is being tackled within hospitals, but wider changes have to be implemented before progress becomes apparent.

When asked what medical students should be doing now to help pave the way for the intern year, Ken’s advice is clear: “Put yourself forward. Talk to as many patients as possible, practice taking histories, and performing physical exams when you get the chance. Don’t hold back - everything that’s good for you as a student is nerve-wracking”!
The Long Game

Interview with Dr. Rhona Mahony

Written by Neasa Conneally Sarah Murphy
Dr. Rhona Mahony; Consultant Obstetrician and the first female Master of the National Maternity Hospital, on her career, memories of her time in UCD and being a prominent voice and advocate for better maternal and infant care in Ireland.

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Do you think being a woman makes any difference to how you carry out your role?

Not at all. People say “The first female Master?” well, I’m the first female that applied to the job here so that takes care of that!

What do you need to be Master?

You need to be a good obstetrician. You need a good insight into complex foetal-maternal medicine problems because we might have very difficult decisions to make for patients and it’s really helpful having a clinical background like I have because it helps me understand, when it comes to complex decisions, what are the pitfalls, what are the difficulties and what might the outcomes be. On a strategic level, I think of my own daughters growing up and wonder how maternity and gynaecological services will be for that generation. I like to think they will be better. I think I’m very driven by that overall picture of how should it be and could be for women in Ireland.

Is there such thing as a typical day for you?

No, that’s the beauty of it. I am usually in the hospital by 7AM to get a feel of how things have been overnight. At 7.30 we have a handover meeting so all our NCHDs (non-consultant hospital doctors) meet, we look at what happened the night before and we try to identify the patients that we’re worried about and make sure that we have identified women with potential problems so that that nobody gets dropped on the handover.

We also use it as an opportunity to debrief a little bit, sometimes it can be traumatic for young staff who might have had a very difficult delivery. We’re very into learning from everything; we’re not into blaming or into pointing the finger.

We also use it as an opportunity to learn from everything; we’re not into blaming or into pointing the finger.

How do you find balancing your clinical practise with your duties as Master?

Lots of hours, I have to say, but I love clinical practice. People say to you “as Master, perhaps you should don’t any clinical practice, you should just be the CEO” but in terms of motivating myself and inspiring myself – seeing babies being born keeps me sane and keeps me connected. On a very important level it also keeps me very connected to the hospital so I’m not seen to be some distant figure issuing instructions. People see me at four in the morning, up to my tonsils in trouble, like everyone else! I also take part in the call rota, I think that does help when you’re trying to bring charge with you, that people feel that you’re part of the team and they will come with you.

Do you think that the law changes nothing really; it essentially legislates for the X Case. I think a lot of people thought the law was introduced in response to the Savita Halappanavar case but not at all, it was actually in response to the A, B and C v Ireland cases in the European Court. The Supreme Court interpreted the Constitution in the X Case to permit termination of pregnancy if there was a substantial risk to a mother’s life caused by complications of pregnancy – a risk which could only be removed by terminating the pregnancy. However, there was no clear process whereby a woman could determine if she qualified termination of pregnancy on the grounds of risk to her life. So the European Court changed Ireland with providing women with such a process.

So I felt that if there was to be a discussion, that doctors should take part in that and give their medical experience over many years because the issue of maternal mortality very much belongs in our sphere and it was very important that any myths might be dispelled.

I didn’t appreciate the level of attention that it would bring upon me and I suppose I found that quite difficult because I wasn’t prepared for it. It’s not that I didn’t think there’d be some attention given but it was a little more than I had anticipated.

So it was a very interesting time. Would I do it again? Yes, I think it was my duty and I think I gave my honest medical opinion based on my factual experience and I think that was the right thing to do.

Recent events have shown that perhaps there is still some uncertainty over what the legislation actually means, would you agree with that?

I think that the law changes nothing really; it essentially legislates for the X Case. I think a lot of people thought the law was introduced in response to the Savita Halappanavar case but not at all, it was actually in response to the A, B and C v Ireland cases in the European Court. The Supreme Court interpreted the Constitution in the X Case to permit termination of pregnancy if there was a substantial risk to a mother’s life caused by complications of pregnancy – a risk which could only be removed by terminating the pregnancy. However, there was no clear process whereby a woman could determine if she qualified termination of pregnancy on the grounds of risk to her life. So the European Court changed Ireland with providing women with such a process.

I think that a lot of people thought that the law was going to somehow revolutionise things, it never set out to do that and so it caused disappointment on both sides, because for the people that got labelled “pro-life”, and I hate labels, they felt that it went too far and for the group that might get labelled “pro-choice”, they felt that perhaps it didn’t go far enough but the law was never going to do anything different. Some people were unhappy that it did not deal with other aspects of complex pregnancy including rape and fatal fetal abnormality. These remain uncomfortable topics, not least for women affected, and I think the discussions and debates are far from over.

I also don’t think that any law will take away the complexity of life. The law is there to protect as much as possible, but humans are very complex, life is very complex, and reproduction has got to be one of the most complex aspects of life. It’s glorious and fantastic, but fraught with all kinds of physical, ethical and moral challenges.

I feel very much that a medical opinion should be given during the hearings because they addressed the very restrictive domain of risk to life for women and I am aware from my practice that at times there are complications of pregnancy that can result in women dying. They’re rare, they’re very infrequent, but they are there.

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Written by Neasa Connolly
Sarah Murphy

Healthcare Perspectives
The Long Game... Interview with Dr Rhona Mahony

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UCD Student Medical Journal
and we have got to realise that people like everything to be black and white and that's where Ireland really struggles, we people with different opinions? I think everyone is different and the question is important we acknowledge that and we give all the support we can to these women and their families to navigate that very tragic circumstance.

Some women, on the other hand, will find the idea of going through that pregnancy and delivering just absolutely impossible, so everyone is different and the question is how do we within our society cater for people with different opinions? I think that's where Ireland really struggles, we like everything to be black and white and we like everyone to think the same way, but people don't think the same way, and we have got to realise that people will approach things differently and what really matters is that we take really great care of our women and our babies.

When talking about increasing staffing levels, how would you improve the retention of medical graduates in Ireland?

There are a number of interesting things happening in Health at the moment. One is that we have lost some of our senior consultants because of reduced voluntary retirement schemes. Approximately 70-80% of a budget in any hospital is spent on staff, if you want to save money the biggest economical thing is to reduce staff. But that can have devastating consequences. So we lost a lot of our most senior doctors and midwives; that was the first thing. The moratorium on staffing levels was a very blunt tool and resulted in gaps, which were subsequently filled by agency staff at great financial expense and at the expense of local departments stability and progress.

Then we find that we have graduates coming out of medical school who are some of the best trained in the world but 50% of them are not taking Irish registration. Some of that will be because they were never going to, they came from abroad and now are going back. But some of that is because they don't see a future in Ireland. And when that starts to happen you have really got to wake up and smell the coffee, both as professionals and as a country. So you have to ask Why? What could it be about working in Ireland that would put young people like you off? First thing is Ireland has got to start by providing the best teaching and training. It won’t do that unless it increases the number of Consultants. Training requires supervision and there is no point in running, as we do, our health service with lots of people in training and only a few people at the top. I think if people know that they would get the very best training then they would consider staying.

We have to address the long hours in some specialties, particularly obstetrics and surgery; you have to address those things so that people can still have a life. I wouldn’t like people coming up through the system that I came up, where we worked over 100 hours a week and I have done so pretty much ever since I was 22. I don’t think that’s a sensible or necessary approach.

Pay is also an issue. We’ve got to take a whole new view of “How do we attract these brilliant new doctors”, and not “These doctors are lucky to get a job in Ireland”, which is where I think we have been. We have a reputation for being toxic employers, which we do deserve and we must now start to come away from that and start making big changes.

How do you balance your long working days with having a young family?

Very badly! Honestly, I’m really lucky; I have a huge amount of support from my husband. He hates me mentioning him but he is extraordinary in his ability to multitask and look after the children and do everything. He’s a total rock - he just keeps the whole house running and he works himself, I don’t know how he does it.

I do give up a lot and others give up a lot on my behalf! I’m aware that I’d love to spend more time with the children. I have missed loads of things and that’s a very difficult thing about being an obstetrician, that your job absolutely comes first, you can’t let people down, you can’t just not go on call, so you have to be there all the time and it does require certain sacrifices to be made. I think it’s worth it in the long run but it is really difficult at times. I always say to my kids, “I’m not always here all of the time but I’m loving you all of the time”.

As a woman in a high leadership role, how would you suggest that the medical profession works with women to allow them to progress in their careers but also have families?

I think it comes back to part of providing training and flexibility. So many young doctors who are coming through now are female and that’s fantastic, but there are going to be differences. People always say you’re being politically incorrect but actually it’s a fact and we might have to plan our work force a little bit differently and we might need to add in a buffer so that maternity leaves can be taken care of.

If you can support women through having their young children, then women will continue to work bringing all their skill and experience to the work place. So you must always take a long view, but I think with the number of women coming through we will have to change how our work force planning is.

Speaking of having a life, what is it you like to do when you’re not working?

When I have a life! I joke that if I wrote a biography recently, it would be “I went to work and then I slept”, that’s it. It would be a short book! No, I’m very interested in life outside of medicine; in fact one of the best things about being Master has been my exposure to all kinds of different organisations, and to things outside of medicine.

But off-duty, I go running because you can do that at any time, you just take a pair of runners and off you go! I love to run around Howth Hill because it’s so beautiful all the time. I like to read, I love theatre, I’m a geek; I love anything that will elevate me. I love eating and the odd glass of wine, if I’m honest. So I love Sunday dinner when everyone’s around the table, my mum and dad, all the family, everyone is talking at each other and no one is listening, that’s really what I love. I’m a very simple girl!

What was your fondest memory of your time in UCD?

Pre-med was just the best year of my life. I met such lovely people and it was so exciting. I loved the intellectual freedom in university, you were surrounded by really clever people, and yet it wasn’t like school. You had a bit of time and when you go out on Tuesday evening, you can catch up on Wednesday so you had a bit more autonomy in how you run your life.

It was very exciting to go into the hospitals as well and be part of that, but I think it was definitely pre-med and that whole feeling of being set free and intellectual stimulation. It was just so much fun but I nearly failed my pre-med exams, I have to say!

If you had one piece of advice for a medical student today, what would it be?

It’s a long game. A career in medicine is going to take a lot of courage, it’s going to take a lot of tenacity and it’s going to take a lot of resilience. So you’ve always got to take the long view all of the time and don’t let the short term knock you. Always be fixed on your longer goal.

And the other bit of advice to everyone is really mind each other, because you are the next generation of doctors. You’re really important and your contribution is going to be enormously important because you shape the next generation coming behind you. So if you have a collaborative way of working, you can achieve so much more by being synergistic. Avoid the petty politics; keep out of it because the kinds of people who love office politics don’t get things done. Getting involved in bitching is a waste of time, it doesn’t get you anywhere. Always look, the whole time, at what you are trying to achieve because getting things done is very exciting.

Want to read more? Go to www.ucdsmj.com
Top 10 Apps for Health Care Students

Written by Sarah Murphy, Nora Tadros
1. DROPBOX

Dropbox is extraordinarily simple, but its usefulness cannot be overstated. It is an online storage space that provides multitudes of students the relief of knowing their files are always safe. It can be used as a backup for all of your lectures, assignments, and any other important documents, academic or not! If any disastrous circumstances strike, whether it involves a crashed or missing laptop, or an accidental delete, all of your documents are completely safe and you can redownload them at any point! Any documents that you choose to upload are well protected and are shown to others only if you allow them to be. Another extremely useful feature is the ability to share documents so others are able to access this information as well. This makes it extremely useful for group projects or any situation where multiple people need access to one source of information.

2. BLACKBOARD

An absolute must for almost any college course in UCD! The Blackboard app allows you to access any information about your modules while you’re on the go, including lectures, and announcements. Additionally, you can allow Blackboard to send you notifications to update you when any lectures, announcements, or other material has been uploaded. This app is fundamental for easily staying up to speed with your academic modules at all times!

3. NEW ENGLAND JOURNAL OF MEDICINE, THIS WEEK

This app from New England Journal of Medicine (NEJM) allows medical students to easily keep up to date with recent NEJM articles. It includes articles on medical research, and review articles on topics important to clinical practice as well as biomedical science. It also has an images, audio, and video section which serve to educate students on important medical conditions and procedures. The NEJM also has a couple other apps, such as the NEJM Image Challenge App, which are dedicated solely to education on medical conditions, as well as allowing the student to test their knowledge.

4. EPONYMS

Not just a medical dictionary, Eponyms also contains definitions of procedures, syndromes, signs, anatomical locations and everything under the sun associated with medicine. This app is immensely handy if there is a term you come across in a lecture or assignment that you have not seen before. The explanations are clear and concise so it’s just like having wikipedia in your pocket. An important feature of this app is that this knowledge base can be accessed anywhere at all because no access to the internet is needed!

5. DIAGNOSTIC RADIOLOGY

A must for anyone trying to understand and visualise radiology. This app includes clear pictures of different anatomical regions and organs from multiple different planes. You are also able to zoom through the images to see different perspectives of the region. All the images are exceptionally well labelled so you actually know for sure what you are looking at! There are actually a few different versions of this app with most of them being free and one paid.

6. FIGURE 1

Famed as the “Instagram for Medical Professionals”, Figure 1 will allow you to share, rank and discuss medical images from around the world. Similar to Instagram, by using a description or hashtag you can search for images and if no such image exists, you will be redirected to a different search engine, such as Google. Figure 1 allows you to discuss diagnosis and treatment with other experienced peers, to broaden your knowledge by viewing both rare and textbook cases and give you the opportunity to familiarise yourself with x-rays, charts, MRI and CAT scans. Whether you want to learn or want to mindlessly scroll through another social networking app (with a twist), this is an invaluable app to get!

7. FACEBOOK

So universal it is often over-looked, the Facebook app allows you to keep up to date on social events and course groups. Additionally, it keeps you in the loop for group projects and every academic resource shared by your peers. Although a small amount of willpower is needed to close the app during lectures, it more than makes up for it’s potential distraction by allowing students to stay in both the social and academic loop effortlessly.

8. MEDSCAPE

For anyone who is already familiar with the desktop version of Medscape, there is no doubt you can appreciate all it has to offer. Incredibly the mobile app has even more features. Firstly a drug reference for current prescribing, dosing and even pregnancy guidelines, furthermore it offers over 120 medical calculators for anyone who struggle to remember any of those pesky calculations. There are also disease and condition references, complete with presentation, work-up and treatment. Finally, their news section will keep you totally up to date with the latest articles written by a team of experts in a range of specialties.

9. FIRST AID BY IRISH RED CROSS

Simple and free. This app is perfect for any health care professional, or anyone period. It will provide one with instant access to information that will enable one to handle common first aid emergencies, as well allow one to ring 112 directly from the app itself. The app is complete with videos, step-by-step advice and quizzes, which make it very easy to to know first aid. One of the best things about this app, is that all content is preloaded, which means you can access all information even if you don’t have reception or internet connection. This app is a definite must.

10. READ BY QXMD

An app that allows you to bring medical journals and literature together in a magazine format. It also enables you to download studies, journals and articles from a variety of sources, including Pubmed, so you can reference them at any time, even on the go. This will ensure you are kept up to date in all specialties and will allow you to reference when writing reviews or even studying.
UCD Student Summer Research Awards Programme 2014: Three Experiences

Written by Cathal Ahern, Peter Foye, Caroline Moran
1. CATHAL AHERN, STAGE 4 UNDERGRADUATE MEDICINE AND SSRA FINALIST 2014

**Project Title**
A novel mind-map-slideshow hybrid for the standardised, interactive and graphical presentation of pathology topics.

**Supervisors**
Dr Peter Holloway, Mr Adam Tattersall

**Location**
Teaching and Learning Education Group, School of Medicine and Medical Science, UCD

“Power corrupts. PowerPoint corrupts absolutely.” – Edward Tufte

The summer of 2014 brought with it the pleasure of working with Dr Peter Holloway, Special Lecturer and Educationalist at UCD SMMS, on an SSRA project. Our work concerned the development and evaluation of a new presentation platform, inspired by perceived problems with the use of presentation software (e.g. PowerPoint) in education.

PowerPoint is widely criticised in educational and psychological literature.1-3 For having little grounding in the theories and science of learning, Edward Tufte, a pioneer in the field of information design, leads the charge against PowerPoint. His book ‘The Cognitive Style of PowerPoint’, argues that PowerPoint’s linearity and rigid structure - the way it progresses as a series of equal-sized boxes - forces simplification of complex content.

PowerPoint also suffers, says Tufte, from a narrow visual bandwidth - the way in which the majority of content is concealed at all times (i.e. only one slide is shown at a time). This can make it difficult to present information that exists as multiple stages or steps, or is inter-related in nature. Consider how to present in PowerPoint, the muscles and movements of the lower limbs, the coagulation cascade, or the life cycle of malaria. You might be able to cram these topics into 80 slides, but, viewers are likely to forget the slide that went before as you advance to the next, focusing on snippets of information without being able to appreciate the information’s relationship to what has gone before.

Enter Dr. Holloway, who whipped up a new presentation format: a ‘web-based hybrid mind-map-slideshow’, designed with pathology topics in mind. That phrase wasn’t really rolling off our tongues, so we later called it ‘OverPath’.

OverPath couples a left-sided mind-map to a right-sided presentation slide area in a web browser. The JavaScript-based mind-map gives a visual, interactive overview of a topic. Exploring the interactive mind-map calls up HTML-based slides, which explore the topic in more detail.

**Graphical representations like mind-maps are justified in learning theory as providing overviews of concepts, offloading some processing burden to the visual brain and relating new learning to previous knowledge.**

The brain organises knowledge into hierarchical frameworks. Tools that emulate or facilitate this process can enhance learning.4 Learning is also enhanced when continuous and large topics are broken down into small, learner-controlled sections,5 as in the mind-map.

Why not try it out yourself at the link below?

http://www.url.ie/velo

The methods and results for this project have been published elsewhere, so I won’t go into detail here, but - after developing OverPath further, we conducted a survey, to which 40 medical students responded, which found a statistically significant (p<0.001) preference for OverPath over a static PDF analogue in terms of perceived usefulness. This was a great vindication of our work.

As a student, it is a great feeling to be able to contribute to the future of medical education. This is part of what the SSRA programme offers you. Medical education projects, specifically, benefit from the counsel of their peers and faculty advisors and at weekly meetings. This real-time feedback helped substantially with staying on top of an evolving project and with solving problems as they arose. This was something that other SSRA students, working mostly alone, ran into issues with.

The next step for our team is to investigate whether or not OverPath objectively enhances learning. We hope to conduct such a case-control-like study looking at OverPath’s effect on exam performance soon.

### References
I made leaps in understanding the topic. The acquisition of in-depth knowledge on one given topic was very rewarding and put into perspective the complexity of biological processes and the potential for improvements in medicine when such processes are fully understood. The literature review made me realise how much modern medicine still suffers from scant understanding of the molecular mechanisms and still relies on clinical outcomes as was the case with the initial use of aminopterin in leukaemia.

The SSRA experience allows medical students a nice start on the path to becoming proficient translational practitioners. The projects allow students to improve critical thinking skills, and the scientific literacy involved with conducting research, presentation and publishing of it. Even application writing. I learned while submitting for the Wellcome scholarship, is an art form in itself and a highly prized skill when it comes to grants for the laboratory. Participants gain valuable laboratory experience in key techniques used commonly in medical investigations and research. Understanding the processes and minutiae of laboratory tests allows students to appreciate the results, as in the case of Western Blotting and its use in anti-HIV antibody testing in the clinical setting. Feelings of ineptitude crept up every now and then, and so felt almost absurd trying to get proficient and confident in laboratory work in a short eight week period. When it came to the experiments, I sometimes wondered whether a small mistake or omission on my part could skew the results. I lacked confidence when providing conclusions. However after some rumination, doubts turned into moderate assertiveness. I realised that I did the work to the best of my abilities. This realisation allowed me to take pride in the results and conclusions that I presented at the 2014 SSRA adjudications and in the abstract for publication in the Irish Journal of Medical Sciences.

Getting immersed in a scientific environment was a serene and enjoyable experience. The hours were quite flexible but generally the project involved a nine-to-five schedule in the laboratory with out-of-hours time spent reading papers and filling out the infamous laboratory notebook. I also devoted weekly instalments of ‘This Week in Virology’ (TWIV) a podcast for virology aficionados. At times, reading the scientific literature on molecular biology felt like deciphering Sumerian cuneiform, a completely foreign, esoteric language full of hard to grasp acronyms and diagrams. But with persistence I experienced amazing moments of clarity in which
Bewilderment:
A Symptom of, & Solution for Empathotoxicity

Written by Matthew Shipsey
“Attention! Here and now!”

“Did you ever wonder...” he begins.

“I see that not lovely, and subtle,” she asks.

“If you think about that, it’s pretty amazing,” he says.

Olé! Olé, olé, olé!

What is this delight, flowering fleeing always earth?

What is being? What is truth?

Blossoms rupture and rapture the air.

All hover and hammer, time intensified and time intolerable, sweetness raveling rot.

And I was alive in the blizzard of the blossoming pear, myself I stood in the storm of the bird-cherry tree.

It was all leaflife and star-shower, unerring, self-shattering power, and it was all aimed at me.

Bewilderment. This is a condition with which all medical students are well acquainted. Walk into an embryology anatomy lecture, and the symptoms will be writ large. Take a peek... traced to the seemingly endless amount of things we can know about the seemingly endless amount of things we need to know.

But bewilderment is a fascinating condition, and the natural history does not end morbidly. Bewilderment, writes one American poet, is “a way of entering the day... an enchantment that follows a complete collapse of reference and reconcilability.”

While the collapse sounds familiar, it is the enchantment with which we should try to relate, and on a daily basis.

How to be enchanted? How to be beguiled, by bewilderment? Follow our poet, Seamus, and noli timere. Don’t be afraid.

(And, if you can, see the sheen of truth through the stain of trite.)
“Noli Timere”

By many, many accounts, there is much to fear in our particular, precarious future as physicians. Indeed, there seems to be a philosophical pandemic in the profession, an outbreak of dissatisfaction, distress, depression. Only 40% of American physicians would recommend the career to their children. Moreover, burnout is said to begin as soon as you enter the hospitals. That is to say, it begins in medical school. The notion of medical school as a “empathoasis” began picking up serious traction when a systematic review of research in medical students and residents found nearly one half of those surveyed met the criteria for burnout (exhaustion, depersonalization, and reduced satisfaction in performance). Painful though it is to report, 11% were found to have been suffering from suicide ideation.x

My fear is that the dehumanizing process of the medical system has already begun, insidiously. When the “zoo of the new” in which we trample daily effects only wringing of hands, when our educators’ call to bewilderment fails to enchant, you fear the choice of fear is being made for us. And all the burnings from downsfield suggest that this is a choice not easily unchosen.x

A system predicated on restoring humans to the full health which instead is destroying the mental and physical health of the humans dedicated to that restoration; insidious, indeed.

But, if Viktor Frankl is to be believed, “everything can be taken from a man but one thing: the last of the human freedoms - to choose one’s attitude in any given set of circumstances, to choose one’s own way.” Seventy years ago, Frankl emerged from the concentration camps with this message to tell: “the choice is always there, and it is yours to make.”

The call is to be answered. The compassionate and miraculous doctor you’ve dreamt of becoming may well be pleading at the other end of the line.

“Religious Truth is not only a portion, but a condition of general knowledge.” xi

“Glimmerings are what the soul’s composed of.” xii

Venturing to mention a word like “soul” to a postmodern audience, let alone a scientific one, is a precarious undertaking. Aligning “religious” besides “truth,” and putting both astride “general knowledge,” as our college founder Cardinal Henry Newman famously did in his “Ideas on a University,” is probably as likely to induce apoplexy as grade IV hypertension.

To entertain the possibility that there is wisdom in this discussion of truth, and knowledge, let us pare back the burdensome “R” word, the same way “faith itself sometimes needs to be stripped...and returned to its first, churchless incarnation in the human heart,” as Christian Wiman, an American poet has it.xiii

This, I think, leaves us in view of the soul’s glimmering splendor, and it is in this light, and through this light, that one might find a way to answer the call. Wiman again:

“The soul is not simply the agent that does the seeing, it is in some way the things that are seen; or, perhaps more accurately, the soul is the verb that makes an exchange between the self and reality — or the self and other selves — possible. It is the soul that turns perception into communication, and communication — even if it’s just between one man and the storm of atoms around him — into communion.” xiv

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Instructions for living a life:

Pay attention. Be astonished. Tell about it.xv

- Mary Oliver

The bottom line is that we have all worked so hard for our privileged seat at the precipice of life’s circumference. Being alive to the amazing experience of being alive, of being and living, the glimmerings of your soul in communion with the elegance of hairpin loops and hand-held human-hearts, is to be enchanted by the bewilderment. It requires attention, and discipline, “this is water, this is water.” But someday quite soon, it may well help you to heal, to restore a life to wholeness, to health. xvi

And if you think about that, it’s pretty amazing.
Get a BOI student credit card with free worldwide multitrip travel insurance included.

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