Personal Approaches and Factors that affect Willingness for Bone Marrow Donation in Singapore

CHP Group 3

NUS YLLSOM Year 4
Bone Marrow

What is the Big Deal?

KEEP CALM AND BE BONE MARROW DONOR
Introduction

- Indications = Neoplastic & Non-Neoplastic
- Haematopoietic Stem Cell transplant is the only definitive cure
- Bone Marrow Donation and Transplantation is the most established form of effective treatment for these diseases
Transplant Request Outcome

1 in 4 chance to match among family

1 in 20,000 chance to match in the general population

- Matched within Family
- Matched in the Population
- Not Matched
Anually

10,000 Require BMD
~70% Match Rate

USA
Source: USA Bone Marrow Registry

Transplant Request Outcome

90%
5%
4%

Matched within Family
Matched in the Population
Not Matched
Annually

USA
10,000
Require BMD
~70%
Match Rate
Source: USA Bone Marrow Registry

Singapore
500
Require BMD
10%
Match Rate
Source: Singapore Bone Marrow Donation Program
USA
Source: USA Bone Marrow Registry
9,000,000 Registered Donors
2.8% of Population

Singapore
Source: Singapore Bone Marrow Donation Program
55,000 Registered Donors
0.8% of Population
Be The Match Registry®
(9 million total)

- Caucasian - 74% (6.5 million)
- Hispanic/Latino - 10% (860,000)
- African American/Black - 7% (650,000)
- Asian/South Asian - 7% (610,000)
- Multiple Race - 3% (300,000)
- American Indian/Alaska Native - 1% (100,000)
- Native Hawaiian/Other Pacific Islander - 0.1% (13,000)

Numbers, percentages and totals may not coincide due to rounding.
anyone between 18-50 years old can register as a donor
How **marrow donation** works:

1 in 500 members go on to donate.

Doctors search for matches for their patient.

Based on 7 out of 8 HLA Markers matching.
Direct Aspiration
Bone marrow aspirated from the iliac crest under GA

Peripheral Blood Stem Cells
Haematopoietic stem cells collected from the blood and concentrated after stimulation by GCSF
Limited literature specific to Bone Marrow Donation

- In general, understanding of attitudes towards BMD borrow heavily from blood donation or solid organ / tissue donation
- Most literature based on Caucasian Heavy Populations
- No studies based on potential donor populations
- Understanding of local attitudes towards BMD is largely anecdotal

Singapore has a low rate of bone marrow donation

Highly heterogenous and multiracial ASIAN society which would reflect a variety of attitudes and perceptions towards bone marrow donation
Personal Approaches and Factors that affect Willingness for Bone Marrow Donation

Qualitative Study
- Explore Knowledge, Attitudes and Perceptions (KAP) of people in-depth
- Develop a theory of how people think about bone marrow donation

Quantitative Study
- Test factors and theory as developed in Qualitative study
- Evaluate how these factors vary across different populations and demographics
Qualitative Study
Interviews & Model Development
Methodology

- Grounded Theory Approach
  - Development of a new theory without biases from existing literature
  - Constant comparative method

+ Critical Realist Paradigm
  - Assuming objective reality
  - Keeping in mind biases
  - No *a priori* hypothesis
Developed in English
Translated to other languages (Mandarin, Malay)

**Common Ideas on Tissue Donation**
- Participants knowledge of donation
- Personal response to donation
- Reflection on willingness to donate

**Additional Items**
- Free association for words [what words would you use to describe BMD]
- Reflecting on differences with other types of donation
- Provision of information and reassessment of views
Purposive Sampling

- Maximum variation
- Snowball sampling
- Negative cases for validation
In Depth Interviews:

- Time & Place of interviewee’s convenience
- Light refreshments provided
- Choice of English, Mandarin and Malay

- Written consent obtained
- No identifiable data
Methodology

Collection & Processing

Audio Recording + Translation → Transcription + Analysis
Methodology
Collection & Processing

Open Coding
Allowing themes to emerge without prior assumptions

Axial Coding
Grouping of themes along axis of general factors

Framework Method
Tabulation of frequencies of factors and themes
3 readings per transcript by different researchers to triangulate codes
- Minimum 1 interviewer involved
- Consensus between at least 2 researchers
- Constant comparison: Code re-evaluation; Highlight deviant cases
- Reflexive reflection
Results

- 16 participants were interviewed

**saturation = no new themes or categories surface in the interviews**

- Reached saturation at 11

- Cases 12 - 16 were validation studies

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<th>Number</th>
<th>Gender</th>
<th>Age group</th>
<th>Ethnicity</th>
<th>Religion</th>
<th>Education level</th>
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<td>Secondary school</td>
<td>Married</td>
<td>Have children</td>
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</tbody>
</table>
Demographics
Taking a Look at the Sample

**Gender**
- Male: 50%
- Female: 50%

**Marital Status**
- Married: 56%
- Not Married: 44%

**Childbearing Status**
- Children: 50%
- No children: 50%
Demographics

Taking a Look at the Sample

Race

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<th>Count</th>
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*No Indian participants were obtained*

Religion

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<td>Christian</td>
<td>6</td>
</tr>
<tr>
<td>Muslim</td>
<td>4</td>
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</table>

*No Indian participants were obtained*
Demographics

Taking a Look at the Sample

Education level

- Secondary: 3
- Polytechnic: 4
- Junior college: 1
- University: 8

Age groups

- 21-30: 7
- 31-40: 3
- 41-50: 6
Themes clustered in Factors

- Information
- Attitudes
- Values
- Circumstances
Lack of Information about BMD in General
“…this bone marrow thing seems to be very quiet, seems like there's no one talking about this…”

Lack of Information about process of BMD
(even those who have heard of BMD before are not clear about process of pledging and donation)
“…You do not go and volunteer, and I don't even know where to go and give my bone marrow…”

Significant Misconceptions
“…I don’t think bone marrow [can] regenerate so donating [a] finite resource is quite risky…”
Attitudes

- Fear of the Procedure
  ...
- Fear of Complications
  “…I suppose that's (not knowing the risks) the greatest barrier for me in actively donating my bone marrow…”
- Level of Information affects Attitude
  “…Because people are always afraid of the unknown…”

Information

individual impression of BMD and feelings (positive / negative)
- **Helping others is a good thing or even a duty**
  “... I can save someone’s life and I thought it was very noble...”
  “... It’s my responsibility. Nothing to feel great about...”

- **In-Group Altruism**
  “... first priority is always your family, friends ... we are made to protect the people we know better”

- **Experiences should be relatable**
  “... it would be good if we could have put a face on things...”

- **Religious Beliefs**
  “... Taoist belief that you shouldn’t cut open the body much ...”
• **Donation is inconvenient**

  *Requires a lot of time*: “… [It’s] more the time I’m incapacitated [that bothers me]. Cannot conduct physical activity for some time…”

  *Might affect their work*: “… May need to take one or maybe 2 weeks of leave to go for the actual procedure and recover…”

  *Affect their ability to take care of their family* during hospitalisation and recovery, most pertinent for mothers and housewives

• **Opinions of Family and Friends**

  “… [My mother is] quite paranoid about blood. So even when I donate blood, every single time she will harass me with a lot of questions…”

---

*practical factors in each individual’s situation which may affect relative ease of BMD*
Negative & Deviant Cases:

active attempt to find interviewees who were DIFFERENT

❖ Unconventional Religious Belief
   “… Islam believes that when we die we are supposed to die with everything intact. So if I give away my bone marrow I'm lacking in something so that is not an ideal way to die…”
Registration

Values

Attitudes

Information

Circumstances

Quantitative

Qualitative

Introduction

Background

Policies

Conclusions

Appendix
Discussion

- Limited existing literature, most of which are limited to donor populations and do not discuss people who have yet to register
- Common themes were also met with in previous studies
  - Holroyd et al 2000
  - Hyde et al 2013
  - Galanis et al 2008
  - Garcia et al 2013
- Model obtained in this study complements theory of planned behaviour
Discussion

Strengths and Limitations

(+)  
- Sufficient number of cases
- Saturation achieved
- Good demographic variation in study population

(-)  
- Under-representation of Races (Indians), Religion (Buddhism etc)
- Under-representation of low socioeconomic status
- Under-representation of objectors to bone marrow donation
Reflexive Reflection:

interviewer’s biases & perspectives may influence the interview

for example: in this study, education was administered by the interviewer during the interview
Quantitative Study

Surveys and Analysis
Methods

- Survey was designed based on the results of the Qualitative Study
culturally appropriate questionnaire based on Qualitative model
Interviewer administered in English, Malay, Chinese

Demographics

Information
Have you heard of bone marrow donation

Education

Values
Bone Marrow donation is admirable

Attitudes
Bone marrow donation is painful

Circumstance
Bone marrow donation is inconvenient

Willingness to Register
1. 3 neighbourhoods were chosen

Sampling Method
Random Sampling

Punggol / Sengkang
Duxton
2. **Condominiums** in the selected neighbourhoods were invited to participate and included upon consent (Zero responded) 

3. Blocks were **randomly chosen** in the selected neighbourhood (by drawing lots) 

4. **All apartment units** in the selected blocks were visited for survey (2 attempts were made to visit each household on 2 separate occasions) 

5. Inclusion criteria = 21 - 50 years old, **Singaporean / PR, conversant in English / Malay / Mandarin** 

6. If multiple possible respondents are in each household, the person with the **next birthday** is surveyed
✤ Minimum Sample Size of 519 needed
  
  - at 5% significance, power 90%
  - able to detect differences of at least 10% between two independent groups

✤ Factor Analysis for model validation (as designed in qualitative study) requires sample size > 750 for optimal results

Bentler PM, Chou CP. Practical Issues in Structural Modeling. Sociological Methods Research 1987; 16; 78
Results

854
Sample Size

37% response rate = respondents / respondents + rejections
Demographics

Analysing Our Sample

Age

Range: 21 - 50
Median: 35

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>21-25</td>
<td>13.3%</td>
</tr>
<tr>
<td>26-30</td>
<td>14.6%</td>
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<tr>
<td>31-35</td>
<td>29.8%</td>
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<tr>
<td>36-40</td>
<td>21.4%</td>
</tr>
<tr>
<td>41-45</td>
<td>14.6%</td>
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<tr>
<td>46-50</td>
<td>11.7%</td>
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Demographics

Analysing Our Sample

Gender

\[ p = 0.69 \]

Marital Status

\[ p < 0.005 \]

Childbearing Status

Sample | National Average
---|---
Male | 47% | 49%
Female | 53% | 51%
Married | 75% | 42%
Not Married | 25% | 58%
Children | 64% | 36%
Demographics

Analysing Our Sample

Race

$\hat{p} = 0.83$

Religion

$\hat{p} < 0.005$

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<th>Race</th>
<th>Sample</th>
<th>National Average</th>
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<td>Chinese</td>
<td>73%</td>
<td>74%</td>
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<td>Malay</td>
<td>12%</td>
<td>13%</td>
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<tr>
<td>Indian</td>
<td>11%</td>
<td>9%</td>
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<tr>
<td>Others</td>
<td>4%</td>
<td>3%</td>
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<table>
<thead>
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<th>Religion</th>
<th>Sample</th>
<th>National Average</th>
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<td>Buddhist</td>
<td>33%</td>
<td>18%</td>
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<tr>
<td>Christian</td>
<td>24%</td>
<td>14%</td>
</tr>
<tr>
<td>Muslim</td>
<td>14%</td>
<td>15%</td>
</tr>
<tr>
<td>Others</td>
<td>9%</td>
<td>17%</td>
</tr>
<tr>
<td>None</td>
<td>33%</td>
<td>17%</td>
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### Housing

- **2 room flat or smaller**
  - Sample: 9.5%
  - National Average: 5.3%

- **3 room flat**
  - Sample: 15.3%
  - National Average: 18.3%

- **4 room flat**
  - Sample: 32.2%
  - National Average: 57.2%

- **5 room flat**
  - Sample: 18%
  - National Average: 24.4%

- **Private Housing**
  - Sample: 19.6%
  - National Average: 19.6%

*p < 0.005*

### Education

- **PSLE or Below**
  - Sample: 4.2%
  - National Average: 11.7%

- **Secondary School**
  - Sample: 18.3%
  - National Average: 26.7%

- **Tertiary**
  - Sample: 11.8%
  - National Average: 11.6%

- **Diploma**
  - Sample: 18.2%
  - National Average: 18%

- **Degree**
  - Sample: 31.5%
  - National Average: 47.4%

*p < 0.005*
What Do You Know

**About Bone Marrow Donation**

**Awareness of BMD**

- **Aware**: 79%
- **Never heard of BMD**: 21%

4 (0.4%) donated bone marrow

43 (5%) already pledged as bone marrow donors
What Do You Know

About Bone Marrow Donation

Acts of Giving

- Blood Donation: 39%
- Donate Cord Blood: 9%
- Volunteer Time: 57%
- Donate Money: 89%
How Do You Know
About Bone Marrow Donation

Source of Information on BMD

- Television: 40%
- Print Media: 39%
- Friends / Family: 22%
- Social Media: 18%
- Dramas: 14%
- School / Company: 10%
- Street Campaigns: 5%
- BMDP Materials: 4%

Knowledge
What Do You Know

About Bone Marrow Donation

Misconceptions about Bone Marrow Donation:

- Bone marrow can be obtained from the blood in a similar way to blood donation
- Bone marrow donation can be done by puncturing the hip bone
- Bone marrow donation can be done by puncturing the spine
- When I register for bone marrow donation I MUST donate my bone marrow when called upon

![Bar Chart]

Wrong: 87%
Correct: 13%
Wrong: 82%
Correct: 18%
Wrong: 20%
Correct: 80%
Wrong: 10%
Correct: 90%
What Do You Think About Bone Marrow Donation

- Monetary Incentive: 19.3%
- Non-monetary Incentive: 41.4%
- Public Recognition: 32.8%

Most respondents did not think that donors should receive incentives.
Why do You Donate

Or Why do You Not?

Willing to Register

- Yes: 24%
- No: 76%

Factors

Introduction  |  Background  |  Qualitative  |  Quantitative  |  Policies  |  Conclusion  |  Appendix
Why do You Donate
Or Why do You Not?

Willing to Register

<table>
<thead>
<tr>
<th>Values</th>
<th>% willing</th>
<th>OR</th>
<th>95% CI</th>
<th>P-value</th>
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<td>22.6</td>
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<td>-</td>
<td>-</td>
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<td>33.3</td>
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<td>1.01 - 2.74</td>
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<td>0.23 - 1.56</td>
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* all Odds Ratio based on comparison to Chinese
Why do You Donate
Or Why do You Not?

Willing to Register

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<td>-</td>
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<td>Yes</td>
<td>27.8</td>
<td>1.35</td>
<td>(0.94 - 1.92)</td>
<td>0.101</td>
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* all Odds Ratio based on comparison to non-religious
Why do You Donate
Or Why do You Not?

Willing to Register

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<td>-</td>
<td>-</td>
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<td>25.9</td>
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* all Odds Ratio based on comparison to non-religious
Why do You Donate
Or Why do You Not?

Willing to Register

- Yes: 76%
- No: 24%

Factors

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<th>Status</th>
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<th>OR</th>
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<td>Married</td>
<td>20.9</td>
<td>0.53</td>
<td>(0.37 - 0.74)</td>
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<td>With Kids</td>
<td>20.8</td>
<td>0.64</td>
<td>(0.46 - 0.88)</td>
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Effect of Marriage / Kids on Perceived Burden:

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<td>&lt; 0.0005</td>
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### Prior Knowledge

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<td>Already knew can donate</td>
<td>1.30</td>
<td>(0.91 - 1.87)</td>
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<td><strong>Considered registering (but not yet registered)</strong></td>
<td>5.50</td>
<td>(3.54 - 8.54)</td>
<td>&lt;0.0005</td>
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### Sources of Knowledge of BMD

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<tr>
<td><strong>Street Campaigns</strong></td>
<td>4.72</td>
<td>(2.51 - 8.93)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>School / Company</td>
<td>2.23</td>
<td>(1.40 - 3.53)</td>
<td>0.001</td>
</tr>
<tr>
<td>BMDP Materials</td>
<td>3.39</td>
<td>(1.63 - 7.05)</td>
<td>0.001</td>
</tr>
<tr>
<td>TV</td>
<td>0.66</td>
<td>(0.47 - 0.92)</td>
<td>0.014</td>
</tr>
<tr>
<td>Fictional films &amp; dramas</td>
<td>0.65</td>
<td>(0.39 - 1.07)</td>
<td>0.093</td>
</tr>
<tr>
<td>Social media</td>
<td>0.80</td>
<td>(0.52 - 1.22)</td>
<td>0.292</td>
</tr>
<tr>
<td>Friends and family</td>
<td>0.98</td>
<td>(0.67 - 1.43)</td>
<td>0.904</td>
</tr>
<tr>
<td>Print media</td>
<td>1.09</td>
<td>(0.79 - 1.50)</td>
<td>0.918</td>
</tr>
</tbody>
</table>

### Willing to Register

- Yes: 76%
- No: 24%
### Knowledge of BMD

<table>
<thead>
<tr>
<th>Knowledge of BMD</th>
<th>OR</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enough information (PRE-)</td>
<td>2.41</td>
<td>(1.64 - 3.55)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>Enough information (POST-)</td>
<td>4.88</td>
<td>(3.44 - 6.94)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>Know how to register (PRE-)</td>
<td>3.08</td>
<td>(2.03 - 4.67)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>I must donate if called upon</td>
<td>1.27</td>
<td>(0.77 - 2.10)</td>
<td>0.345</td>
</tr>
<tr>
<td>Enough donors to meet need</td>
<td>1.49</td>
<td>(0.56 - 3.98)</td>
<td>0.423</td>
</tr>
<tr>
<td>Donation by puncturing spine</td>
<td>1.52</td>
<td>(1.04 - 2.20)</td>
<td>0.029</td>
</tr>
<tr>
<td>Donation by puncturing hip</td>
<td>1.68</td>
<td>(1.13 - 2.48)</td>
<td>0.01</td>
</tr>
<tr>
<td>Similar to blood donation</td>
<td>1.61</td>
<td>(1.03 - 2.51)</td>
<td>0.038</td>
</tr>
</tbody>
</table>

### Acts of Giving

<table>
<thead>
<tr>
<th>Acts of Giving</th>
<th>OR</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donated cord blood before</td>
<td>0.70</td>
<td>(0.38 - 1.28)</td>
<td>0.244</td>
</tr>
<tr>
<td>Donated blood before</td>
<td>2.65</td>
<td>(1.91 - 3.65)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>Donated cash to charity</td>
<td>2.56</td>
<td>(1.33 - 4.90)</td>
<td>0.005</td>
</tr>
<tr>
<td>Volunteered time to charity</td>
<td>1.83</td>
<td>(1.31 - 2.55)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>Values</td>
<td>OR</td>
<td>95% CI</td>
<td>P-value</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>------</td>
<td>--------------</td>
<td>---------</td>
</tr>
<tr>
<td>Donors are very admirable</td>
<td>1.28</td>
<td>(0.85 - 1.94)</td>
<td>0.242</td>
</tr>
<tr>
<td>Only register if committed</td>
<td>1.33</td>
<td>(0.96 - 1.85)</td>
<td>0.091</td>
</tr>
<tr>
<td><em>Registering is a duty</em></td>
<td>6.90</td>
<td>(4.57 - 10.42)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td><em>Desire for Reciprocity</em></td>
<td>3.43</td>
<td>(2.45 - 4.79)</td>
<td>&lt;0.0005</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Incentives</th>
<th>OR</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deserve public recognition</td>
<td>0.72</td>
<td>(0.50 - 1.01)</td>
<td>0.06</td>
</tr>
<tr>
<td>Deserve monetary reward</td>
<td>0.67</td>
<td>(0.43 - 1.03)</td>
<td>0.066</td>
</tr>
<tr>
<td>Deserve non-monetary reward</td>
<td>1.18</td>
<td>(0.86 - 1.63)</td>
<td>0.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group Norms / Values</th>
<th>OR</th>
<th>CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religious leaders support</td>
<td>2.72</td>
<td>(1.82 - 4.08)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>Family support</td>
<td>3.58</td>
<td>(2.57 - 5.00)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>Friends support</td>
<td>3.11</td>
<td>(2.21 - 4.39)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>Colleagues/superiors support</td>
<td>4.20</td>
<td>(2.89 - 6.10)</td>
<td>&lt;0.0005</td>
</tr>
</tbody>
</table>

Willing to Register

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>#</td>
<td>76%</td>
<td>24%</td>
</tr>
</tbody>
</table>
### Attitudes

<table>
<thead>
<tr>
<th>Attitude</th>
<th>OR</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donation = lot of pain</td>
<td>0.63</td>
<td>(0.46 - 0.86)</td>
<td>0.004</td>
</tr>
<tr>
<td>Scared of donation</td>
<td>0.38</td>
<td>(0.27 - 0.54)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>High risk of damage to body</td>
<td>0.39</td>
<td>(0.25 - 0.60)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>Donation makes one ‘exposed’</td>
<td>0.53</td>
<td>(0.34 - 0.83)</td>
<td>0.005</td>
</tr>
<tr>
<td>Donation is highly intrusive</td>
<td>0.49</td>
<td>(0.33 - 0.72)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>Makes body less ‘complete’</td>
<td>0.46</td>
<td>(0.27 - 0.76)</td>
<td>0.003</td>
</tr>
</tbody>
</table>

### Circumstances

<table>
<thead>
<tr>
<th>Circumstance</th>
<th>OR</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>0.53</td>
<td>(0.37 - 0.74)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>With children</td>
<td>0.64</td>
<td>(0.46 - 0.88)</td>
<td>0.006</td>
</tr>
<tr>
<td>Inconvenient to register</td>
<td>0.95</td>
<td>(0.64 - 1.41)</td>
<td>0.802</td>
</tr>
<tr>
<td>Donation takes up a lot of time</td>
<td>0.49</td>
<td>(0.34 - 0.70)</td>
<td>&lt;0.0005</td>
</tr>
<tr>
<td>Donation costs a lot of money</td>
<td>0.82</td>
<td>(0.48 - 1.39)</td>
<td>0.454</td>
</tr>
<tr>
<td>Huge burden to family</td>
<td>0.41</td>
<td>(0.24 - 0.70)</td>
<td>0.001</td>
</tr>
</tbody>
</table>
I have enough knowledge to make a decision about Bone Marrow Donation now?

<table>
<thead>
<tr>
<th>Pre-Education</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>153</td>
<td>121</td>
<td>178</td>
</tr>
<tr>
<td>Neutral</td>
<td>32</td>
<td>122</td>
<td>92</td>
</tr>
<tr>
<td>Agree</td>
<td>11</td>
<td>22</td>
<td>103</td>
</tr>
</tbody>
</table>

There is a significant change in perceptions post education (Wilcoxon signed rank test; p < 0.0005)
Caveats

So who will you donate to

Willing to Register

- 99% willing to donate to Family
- 97% willing to donate to Friends
- 89% willing to donate to Local Strangers
- 85% willing to donate to Foreign Strangers

- 24% willing to donate to Family
- 24% willing to donate to Friends
- 24% willing to donate to Local Strangers
- 24% willing to donate to Foreign Strangers

- 76% Yes
- 24% No

Further Analysis

Caveats

So who will you donate to
# Effect Modification

<table>
<thead>
<tr>
<th>Prior blood donation</th>
<th>Willing to Register</th>
<th>OR (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
<td>3.05 (2.10 - 4.42)</td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Number of participants:
- No: 460
- Yes: 246
### Effect Modification

<table>
<thead>
<tr>
<th>It is my duty to donate bone marrow</th>
<th>Prior blood donation</th>
<th>Willing to Register</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
<td>No</td>
<td>407</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>210</td>
<td>66</td>
</tr>
<tr>
<td></td>
<td><strong>Subtotal</strong></td>
<td></td>
<td>617</td>
<td>111</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>53</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>36</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td><strong>Subtotal</strong></td>
<td></td>
<td>89</td>
<td>31</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td></td>
<td>706</td>
<td>142</td>
</tr>
</tbody>
</table>
## Effect Modification

<table>
<thead>
<tr>
<th>Thought of Registering</th>
<th>Willing to Register</th>
<th>OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
<td>589</td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>48</td>
</tr>
</tbody>
</table>
## Effect Modification

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>Thought of Registering</th>
<th>Willing to Register</th>
<th>OR</th>
<th>(95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>No</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>non-BMDP</td>
<td>No</td>
<td>532</td>
<td>100</td>
<td>4.60</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>37</td>
<td>32</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Subtotal</td>
<td>569</td>
<td>132</td>
<td></td>
</tr>
<tr>
<td>BMDP</td>
<td>No</td>
<td>57</td>
<td>16</td>
<td>6.48</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>11</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Subtotal</td>
<td>68</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>637</td>
<td>168</td>
<td>5.50</td>
</tr>
</tbody>
</table>
Confounder

<table>
<thead>
<tr>
<th>Self-perception of information adequacy</th>
<th>Already Registered</th>
<th>OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inadequate</td>
<td>No: 622</td>
<td>Yes: 83</td>
</tr>
<tr>
<td>Adequate</td>
<td>No: 80</td>
<td>Yes: 58</td>
</tr>
</tbody>
</table>

5.54
(95%CI 3.61 - 8.17)
## Confounder

### Self-perception of Information Adequacy

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>Already Registered</th>
<th>OR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>BMDP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate</td>
<td>569</td>
<td>62</td>
</tr>
<tr>
<td>Adequate</td>
<td>58</td>
<td>24</td>
</tr>
<tr>
<td>Subtotal</td>
<td>627</td>
<td>86</td>
</tr>
<tr>
<td>(95% CI 3.61 - 8.17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>non-BMDP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate</td>
<td>53</td>
<td>21</td>
</tr>
<tr>
<td>Adequate</td>
<td>22</td>
<td>34</td>
</tr>
<tr>
<td>Subtotal</td>
<td>75</td>
<td>55</td>
</tr>
<tr>
<td>(95% CI 3.61 - 8.17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>702</td>
<td>141</td>
</tr>
<tr>
<td>(95% CI 3.61 - 8.17)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Discussion

- State of Bone Marrow Donation in Singapore
- Current Misconceptions in the Population
- Key Factors Associated with Willingness to Donate Bone Marrow
79% aware of BMD
16% think they have sufficient info
5% registered

most are **aware** that BMD exists but are **unsure** whether they want to participate
Procedure of Bone Marrow Donation
(most are unaware of availability PBSC or process of bone marrow aspiration)

Short Education can significantly improve self-perception of information adequacy post intervention
Key Factors
Affecting Willingness to Donate

(+)

- Race (Indian)
- Religion (Christianity)
- Considered registering before
- Past Acts of Giving (blood donation and volunteering)
- Belief of Reciprocity
- Group Norms
- BMDP sources

(-)

- Marriage and Having Children
- Fear of Pain
- Fear of Long-term health effects
- Opportunity cost as well as burden to Family
- Feel that body is left incomplete
## Comparing with Other Studies

**Past Literature**

<table>
<thead>
<tr>
<th>Similarities</th>
<th>Differences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Importance of education [1, 3]</td>
<td>Perceived need for recognition not associated with willingness [3]</td>
</tr>
<tr>
<td>Similar attitudes, values and circumstances that were associated with lack of willingness to sign up [1, 2, 3]</td>
<td>Perception of altruism does not significantly affect willingness to donate [1, 3]</td>
</tr>
<tr>
<td>Possible role of religious beliefs [3]</td>
<td></td>
</tr>
</tbody>
</table>

1. Hyde et al 2014
2. Vasconcellos et al 2011
3. Garcia et al 2013
Evaluating Our Study

Strengths and Weaknesses

- Novel Asian Study on KAP towards bone marrow donation
- Usage of both qualitative and quantitative approaches allowed for in-depth as well as large scale assessment of KAP towards bone marrow donation in Singapore
- Developed and confirmed theoretical model of factors affecting bone marrow donation
- Large sample size as compared to other studies across the world (~200 in most studies)
<table>
<thead>
<tr>
<th>Study Weakness</th>
<th>Defense</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only 3 estates were chosen for surveying which may lead to a less representative sample (selection bias)</td>
<td>Pragmatic choice to allow for sampling of younger demographics. Final demographics ultimately comparable to national census</td>
</tr>
<tr>
<td>Survey was only administered in English, Mandarin or Malay (selection bias)</td>
<td>In retrospect, no respondents were turned away for language reasons as they can converse in English</td>
</tr>
<tr>
<td>Survey was interviewer administered and large number of interviewers can lead to random error (measurement bias)</td>
<td>Standardised training and scripts were provided to all interviewers</td>
</tr>
<tr>
<td>Observer Effect (Social desirability bias): respondent may be more self conscious and over-report on their level of altruism</td>
<td>Survey is completely anonymous and no identifiers are collected</td>
</tr>
</tbody>
</table>
### Evaluating Our Study

**Strengths and Weaknesses**

<table>
<thead>
<tr>
<th>Study Weakness</th>
<th>Defense</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survey administered is self-designed and not validated in large center studies</td>
<td>Survey was designed based on a thorough qualitative study to elucidate range of KAP of Singaporeans</td>
</tr>
<tr>
<td>Response rate was relatively low at only 37% (selection bias)</td>
<td>Attempts were made to pre-empt residents by providing flyers 1 week before visiting, attempts were made to visit units multiple times</td>
</tr>
</tbody>
</table>
Policies

The Game Plan
Intervention Plan

What can BMDP do with this information
Willing to Donate:

33.3% Indians  
25.5% Malays  
14.7% Others  
22.6% Chinese

Though under-represented in the donor pool, *minorities not less willing* to donate
Thought Matters

Need for More Follow Up

<table>
<thead>
<tr>
<th>Prior Knowledge</th>
<th>OR</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Already knew can donate</td>
<td>1.30</td>
<td>(0.91 - 1.87)</td>
<td>0.148</td>
</tr>
<tr>
<td>Considered registering (but not yet registered)</td>
<td>5.50</td>
<td>(3.54 - 8.54)</td>
<td>&lt;0.0005</td>
</tr>
</tbody>
</table>

Follow up on populations already been educated in the past who may have considered registering
Acts of Giving Count
volunteering time, money, previously donating blood etc.

Blood Donors especially
Marriage & Kids dissuade donation
More support to reduce family burden
TV and Mass Media are *most common* sources of information, but are less effective currently.
Medium Matters

Broader may not be better

How to Approach

YouTube

Direct Outreach is *a less common* sources of information, but are more effective currently
Key Information

Pain, Cost, and others

More reassurance on procedures, costs and benefits of donations
Conclusion

- Sign up rates currently remain low
- Most Singaporeans lack sufficient information to make an informed decision and sign up as a donor
- Key Factors associated with willingness to donate are: race, religion, marital and childbearing status, factors affecting perception of bone marrow donation, knowledge of donation process
Bibliography

1. A. Vasconcellos. Knowledge, Attitudes, and Behaviors Regarding the Bone Marrow Registry among College and Medical Students in Rhode Island. Medicine & Health/Rhode Island 2011; 94(10): 302-305.
“Altruism is innate, but it’s not instinctual. Everybody is wired for it, but a switch has to be flipped”

– David Rakoff
Appendix

Things You Do NOT Need to Know
Confirmatory Factor Analysis

- Evaluate the Validity of the model developed in the Qualitative Study based on the results from the Quantitative Study
- Evaluate the relative effects of each factor on the final willingness to donate
Confirmatory Factor Analysis

Weighing the Parameters

1. Specify the model
2. First run with all pre-determined variables
   A. Inspect fit statistics
   B. Remove non-significant variables (p > 0.05)
   C. Remove variables with low loading (factor loading < 0.2)
3. Re-run model with updated variables
Logistic Regression Modelling

- Not easy to detect confounding in some variables due to lower power
- Multivariate logistic regression is hard to perform in our study due to large number of variables
- Dimension reduction using factor scores output from CFA analysis
- Use of factor scores in regression
- All variables other than factors not significant except flat size
Logistic Regression Modelling

- Not easy to detect confounding in some variables due to lower power
- Multivariate logistic regression is hard to perform in our study due to large number of variables
- Dimension reduction using factor scores output from CFA analysis
- Use of factor scores in regression
- All variables other than factors not significant except flat size

Refer to SPSS output file for analysis of Modelling
Theory of Planned Behaviour

- TPB aims to predict behavioural intention and actual behaviour
- Commonly used by researchers as a model to create survey questions
- Our model depicts the thought process and the interplay between factors

**ATTITUDE**
(Behavioural beliefs weighted by Outcome evaluations)

**SUBJECTIVE NORM**
(Normative beliefs weighted by Motivation to comply)

**PERCEIVED BEHAVIOURAL CONTROL**
(Control beliefs weighted by Influence of control beliefs)

**BEHAVIOURAL INTENTION**

**BEHAVIOUR**

TPB aims to predict behavioural intention and actual behaviour. Commonly used by researchers as a model to create survey questions. Our model depicts the thought process and the interplay between factors.
Interplay between Factors

- Information affecting...
  - Attitudes: “Now knowing there is 2 methods and a method that sounds reasonably doable [referring to PBSC] so it has allayed some fears I guess, some fears of pain.”
  - Values: “When the Islamic Association of Singapore educate the population it's not an offence to the religion then majority of them are willing to donate lah.”
  - Values and circumstances: “After you share that information, I think erm I should go for it […] I can tell my family; ‘This is one of the reasons I go through this, because the rate of match is really low, so if the person is really suffering from leukemia and he is actually finding a match it's his only erm so called reason or chance to survive’
Interplay between Factors

- Weighing values, attitudes and circumstances: “It's good intention lah, but only the procedure lah that worries people, [and] in terms of financial before and after the donation.”
Thought Process

- “Ok first and foremost, you need to pass yourself. Do you think you are really willing to go ahead with this? Then you consider whether family members agree or disagree.”
Registration-Donation Equivalence

- Participants considered the act of signing up as seriously as if they were considering actual donation
  - When asked about signing up, responded with concerns not about the registration process but about the donation process
  - Stated that one should only register if certain that one will follow through if called upon to donate
  - Explicitly mentioned that signing up without thinking carefully about donation can lead to pulling out or being ill-prepared if ever called up
Registering for BMD means you are committed to donating:

- **60%** Yes
- **40%** No

“… I don't think you can tell people that oh it's just a cheek swab, don't worry, we will not even call you. Because the person has to be prepared for the possibility lah, which can happen in any day …”

“… Because maybe they don’t know what they’re signing up for, like they just agree to it because it sounds heroic to donate your bone marrow …”

“… I think if I were to sign up I’d also want myself to already be willing to donate, it seems to be quite mean-spirited to find out then to backout, because then you’re leading people on…”
Future Works

- Sample Representation could be improved by increasing the sampling of the under-represented groups in this study (for qualitative & quantitative studies)
- Model fit could be improved by having a bigger question pool and weeding out non-significant questions
  - Model improvement to include demographic factors
- Check factors effect on actual registration instead of willingness to register
- More targeted subgroup analysis looking at ethnic minorities
- Assessment of KAP of actual donors to evaluate the differences between registration and actual
- Intervention studies assessing effectiveness of policy changes as suggested in this study
Validation Studies

- Ideally, multiple rounds of CFA in small pilot studies to optimise question bank before surveying
- Check for test retest reliability
Why do We give education?

- NOT interventional
- Discovered in qualitative study that many people, even those with higher education, had never heard of bone marrow donation and initially felt they could not give meaningful views
- Discovered in qualitative study that educational component does change views
- Discovered that qualitative participants reflected that they could make informed decisions after education
- Knowledge assessed before education given
- Give standardised education component that is similar to that which would be given by BMDP anyway
- Avoid participant randomly answering when responding to items on opinions