



KNOWLEDGE, PERCEPTIONS AND WILLINGNESS TO PARTICIPATE IN BIOBANKING AMONG YOUNG ADULTS IN IPOH, PERAK.

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INTRODUCTION:

A biobank generally refers to structured collections of biological samples and associated data, stored for the purpose of present and future research. It typically handles human biospecimens - such as tissue, blood, urine and information related to the donors. (1) Biobanks have become a necessity to developed countries as they can provide access to large amounts of genetic and electronic health record data, so more efficient further research can be done and more genetic components of diseases can be identified as well as cured.

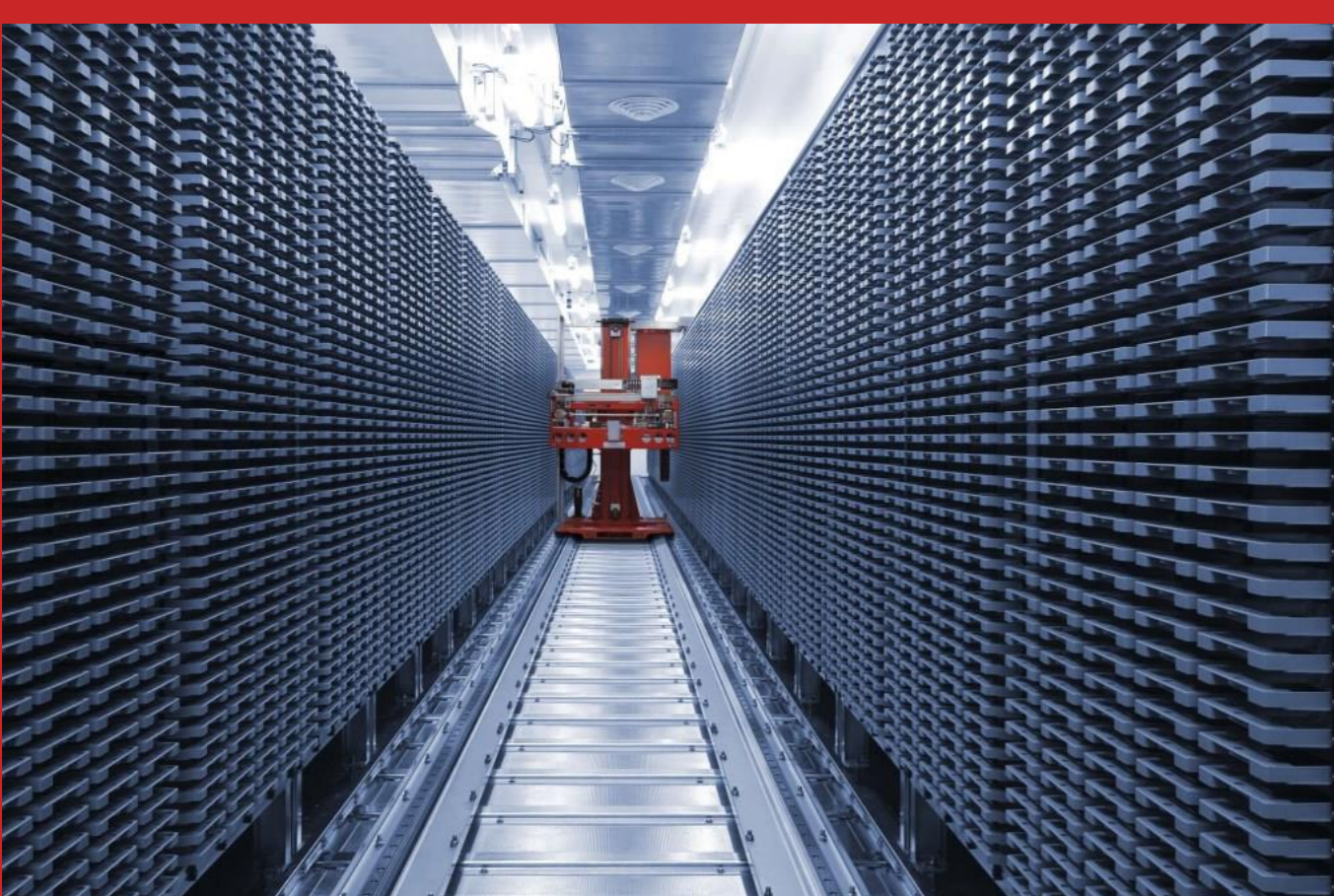
AIMS/OBJECTIVES:

General Objectives

To determine the knowledge, perceptions, and willingness to participate in biobanking among the young adults in Ipoh, Perak.

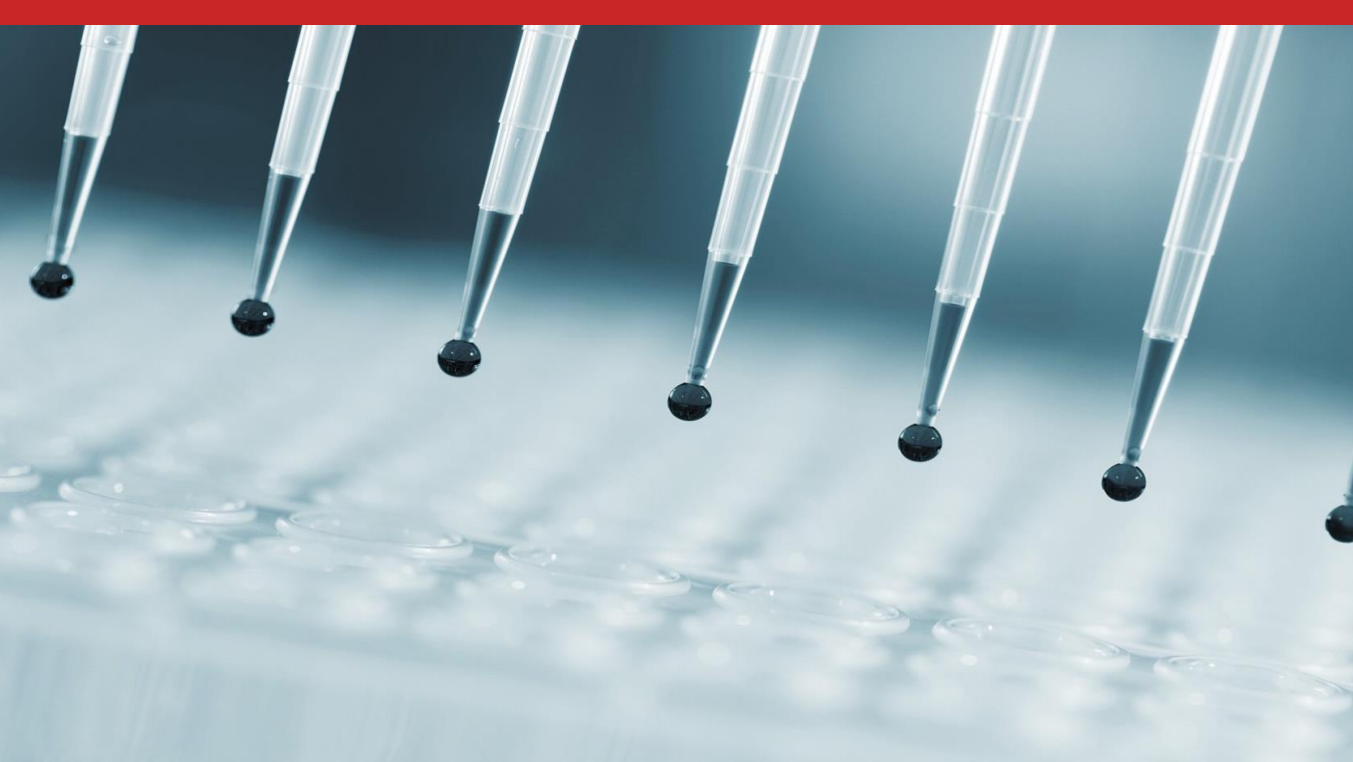
Specific Objective

- To determine the general level of knowledge regarding biobanking among the young adults.
- To determine the perception towards biobanking among the young adults.
- To determine the association between perceptions and willingness to participate in biobanking.
- To determine the reasons for the willingness to participate in biobanking among the young adults.
- To determine the reasons for the unwillingness to participate in biobanking among the young adults.



METHODOLOGY:

A cross-sectional study using a random sampling method was conducted in selected places in Ipoh, Perak from 8-12 January 2018. The pre-designed questionnaire we used consists of 4 parts comprising knowledge, awareness and perception towards biobanks in Malaysia. The data was extracted using Microsoft Excel 2016 and then statistically analysed using Statistical Package for Social Sciences version 23 (SPSS).



RESULTS:

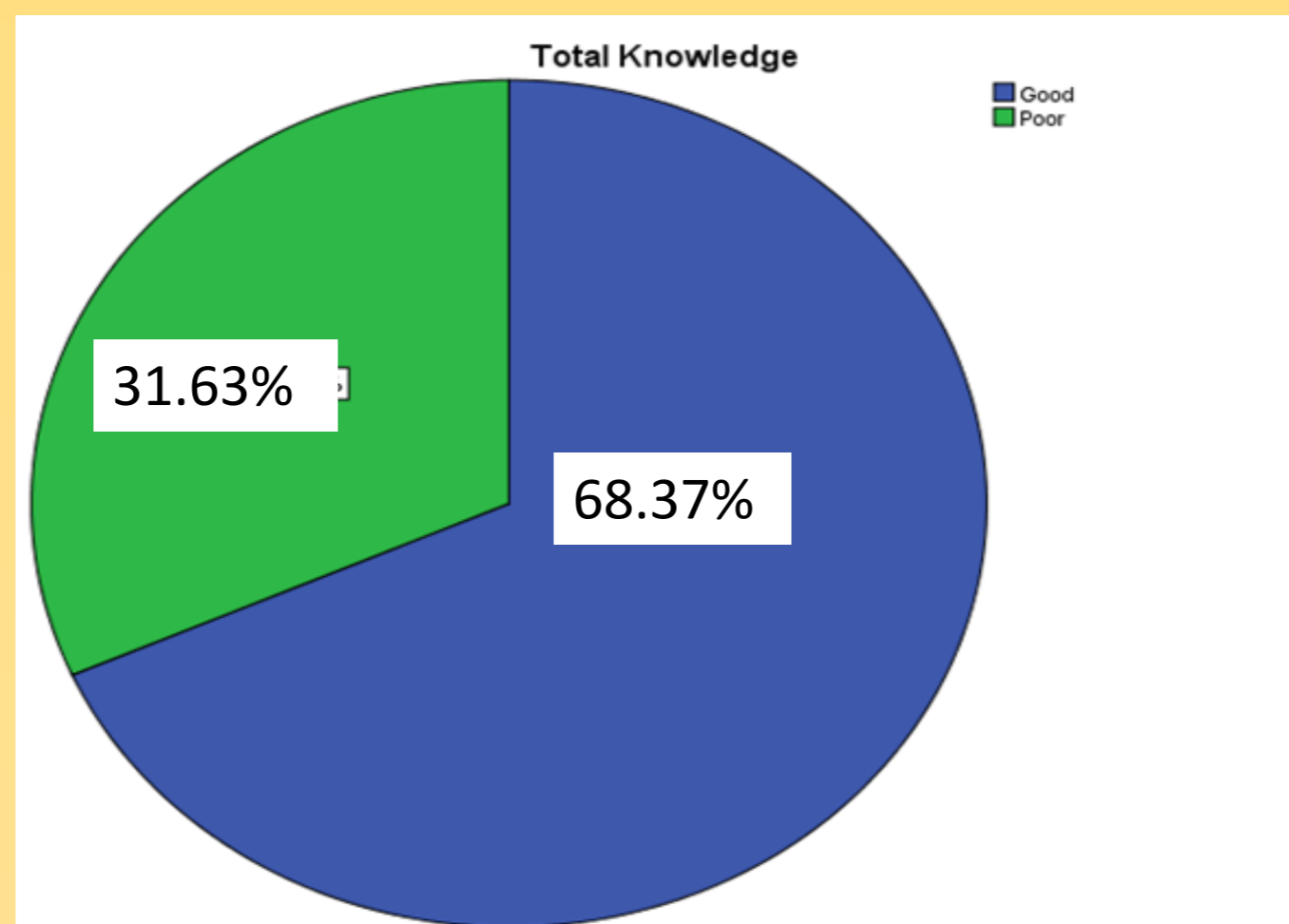


Figure 1: Level of knowledge regarding biobanks among young adults in Ipoh.

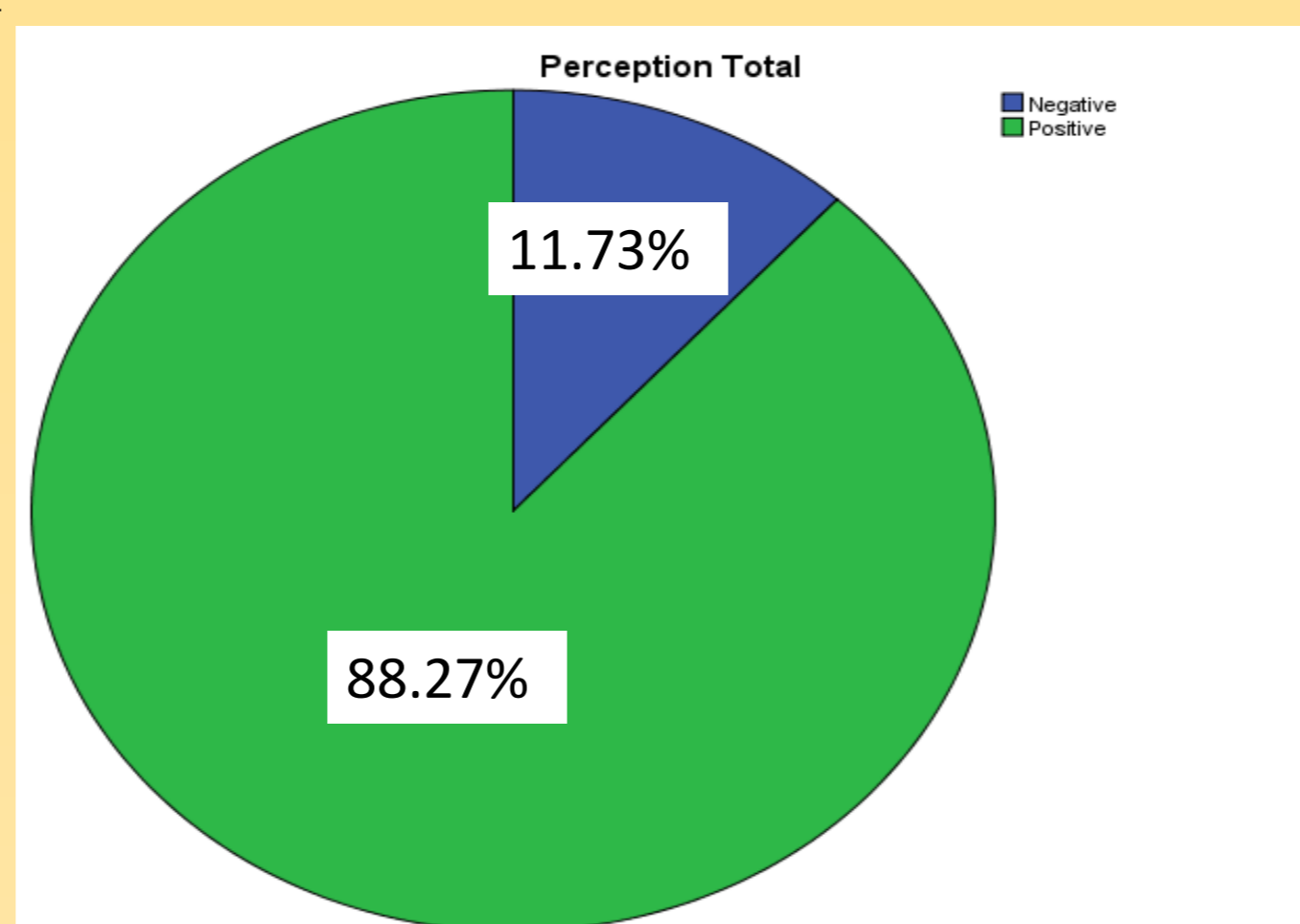


Figure 2: Total perception regarding biobanking procedures.

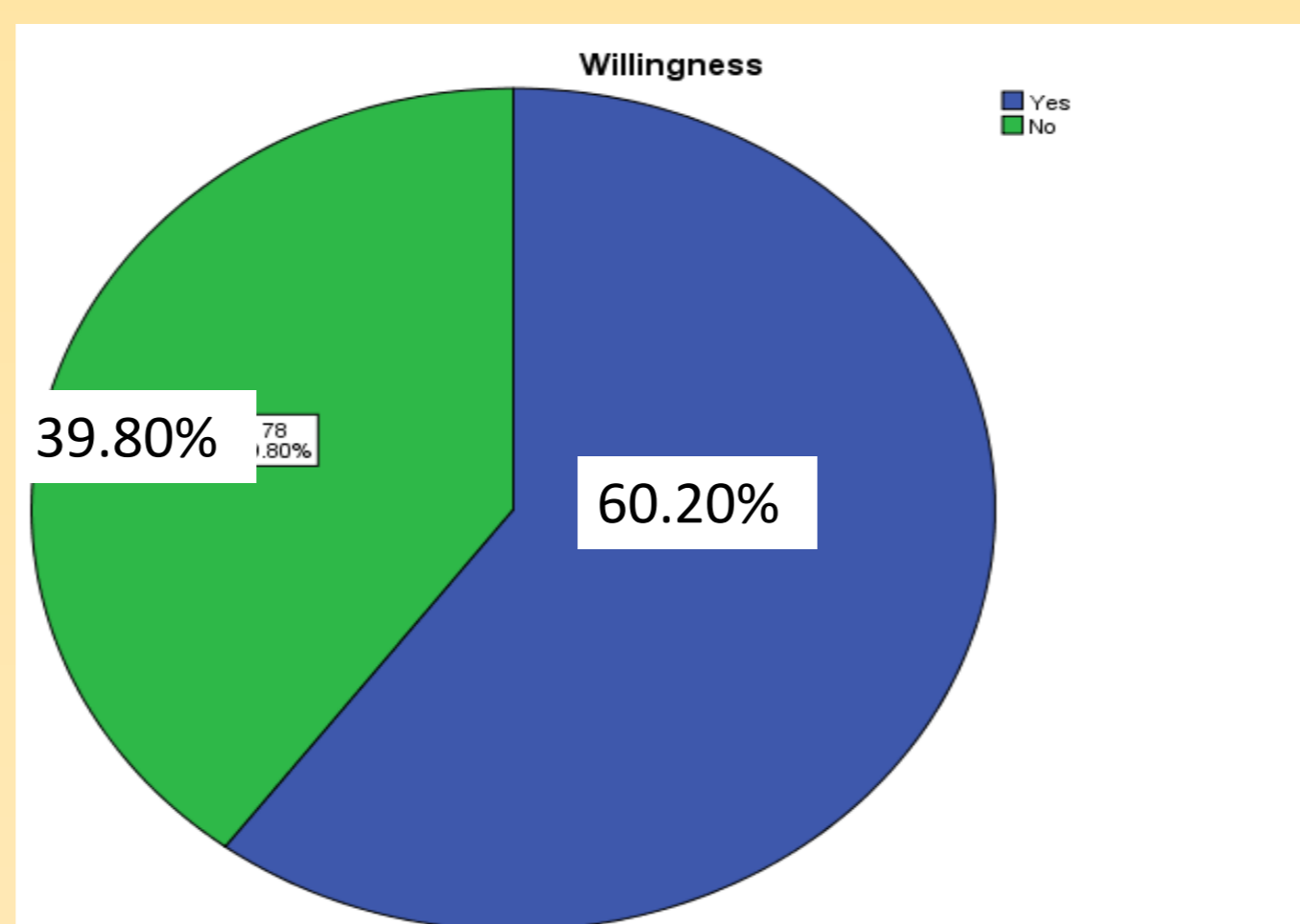


Figure 3: Willingness of respondents for participation in biobanking.

Table 1: Reasons of respondents who are willing to participate in biobanking.

Reasons for Participation	Percentage (%)
For the advancement of the medical research, benefit the society and future generation	88.14
I could be notified about abnormal results	52.54
Sample will already be collected as part of my medical care	45.76
My family and I will benefit	37.29
Biobank is already established as core facility of biomedical Research in developed countries	33.90
Others	5.08

Table 2: Reasons of respondents who are unwilling to participate in biobanking.

Reasons for Non-participation	Percentage (%)
Concerns about misuse of biospecimens in biomedical research.	37.18
Concerned that biospecimens may be used for commercial purposes.	33.33
Concerned that genetic information may be used for discriminatory purposes.	30.77
Fear of needles or injections.	30.77
Concerned about discovering genetic predispositions to some diseases.	28.21
Concerned about confidentiality.	23.08
Others.	16.67
Religious reasons.	5.13

DISCUSSION AND CONCLUSION:

Our results show that a majority of the respondents have good knowledge (68.37%) and a positive perception of biobanking (88.27%). A majority (60.2%) of the respondents are also willing to participate in biobanking. Where association between perception and willingness to participate in biobanking is concerned, our chi-square analysis concluded that there is no correlation between perception (whether positive or negative) with the willingness to participate in biobanking ($p > 0.05$). Our results also show that the main reason for participating in biobanking appear to be driven by altruistic factor, i.e. for the benefit of research and society including future generations. For those who are not willing to participate, the concern seem to be with specimen misapplication in research (37.18%), commercial purposes (33.33%) and discriminatory purposes (30.77%). Religious reasons appear to be the least concerned (5.13%). In conclusion, there is a high level of knowledge regarding biobanking among the young adults of Ipoh, Perak and no correlation between perception and willingness to participate in biobanking.

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