


CONSENTING (NOT) TO PARTICIPATE:
CHALLENGES & OPPORTUNITIES OF INVOLVING
YOUNG PEOPLE IN RESEARCH, MONITORING &
EVALUATION

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Research [Evaluation] is a
moral endeavor that seeks to ensure that the
welfare, autonomy and privacy rights of infant, child and
adolescent participants are adequately protected and
that such protection does not prevent them from
equitable sharing of the burdens and benefits of
research.

Source: Fisher et al., 2013, p. 4

Belmont Principles +

Ethical Principle	Application
Autonomy	<ul style="list-style-type: none"> — Obtain informed consent — Extra protections for those who are not self-determining
Beneficence	<ul style="list-style-type: none"> — Conduct risk/benefit assessments — Minimize risks
Non-maleficence	<ul style="list-style-type: none"> — Conduct risk/benefit assessments — Minimize risks
Justice	<ul style="list-style-type: none"> — Recruit subjects to distribute benefits and burdens evenly — Don't target the vulnerable for convenience
Relationality	<ul style="list-style-type: none"> — Respect existing relationships

- Know relevant legal standards for obtaining IC/IA in your locality
- Follow ethical guidelines
- Reconsider existing frameworks within new childhood frameworks

Sources: Belmont Report, 1979; DuBois, 2005, 2008; Ruiz-Casares, 2012, 2014; Shumaker & Medoff, 2013

Informed Consent, Assent & Dissent

- **IC** = voluntary agreement provided on the basis of sufficient & appropriate information

— PP = Parental Permission

INABILITY RESPECT

↓

- **IA** = individual's voluntary affirmation to participate
- **ID** = non-agreement to participate in specific experiences
- Permission & Assent **Waivers**

Sources: Dockett, Einarisdottir & Perry, 2012; Ford, Sankey & Crisp, 2007

Children in REM

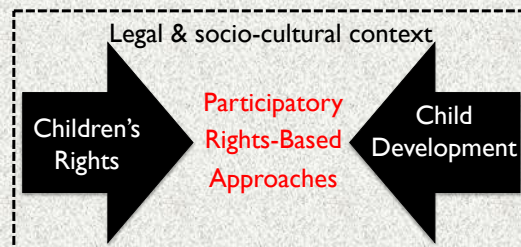
1. New sociology of childhood
 - Children = persons, experts, **agents**
 - Subjects, Consultants, Partners, Directors in REM
2. Children's **rights** & citizenship
 - To (not) participate
 - To be protected from harm
3. **Actively listening** to children (Clark, 2005)
 - not limited to the spoken word
 - a necessary stage in participation

Sources: Clark, 2005; Clark & Moss, 2001; Gilshrist et al, 2013; Prout, 2000; UNCRC, 1989

Participatory Rights-Based Approaches

- Recognize children's right to participate on issues that matter to them
- Provide opportunities for children to exercise agency
- Assume children's competence to indicate A/D

Acknowledge context!



Sources: Dockett & Perry, 2011

Key Elements of IC/PP/IA

1. Access to sufficient & appropriate **information**
2. **Comprehension** & competence
3. **Voluntary** involvement

*** Reflexivity ***

Sources: Belmont Report, 1979; Dockett & Perry, 2011; Phelan & Kinsella, 2013

Providing Info: Essential IC/PP/IA Components

- Study-specific information
 - Study purpose
 - Study procedures
 - Study risk
 - Benefit (direct & indirect)
- Research rights
 - Right to refuse/withdraw
 - Voluntariness of research
 - Confidentiality
 - Alternatives to research



Sources: Afolabi et al., 2014; O'Lonegan & Forster-Harwood, 2011

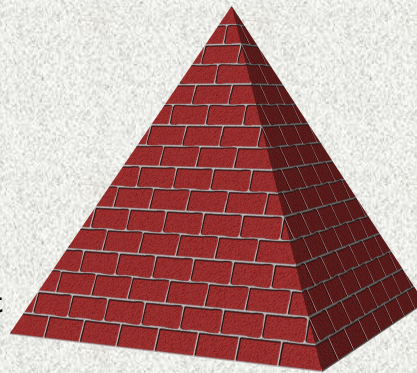
Comprehension & Competence

- Attention to manner of providing information!
- Obligation to ascertain understanding
 - Engage parents in assessment
- Competence
 - Participants competence & influencing factors
 - Ambiguity on how to assess it (Age? Developmental stage? Ability? Context?)
 - Researcher competence & influencing factors

Sources: John et al., 2008; Lambert & Glacken, 2011

Voluntariness

- Coercion?
 - Justifiable persuasion
 - Undue influence
- Power imbalances
- Indicating assent & dissent
 - Identification of subtle or covert signs of refusal
 - Engage parents in assessment



Sources: Belmont Report, 1979; Ondrusek et al., 1998

Challenges in Obtaining PP/IA

- Unavailability
- Misunderstanding
- Over or under-informing
- Balancing personal interests/expectations with evaluation objectives
- Views of evaluation
- Gatekeepers & proxy consent
- ‘Coerced’ participation

Sources: Alderson, 1995; Dockett & Perry, 2011; Okello et al., 2013

Enhancing IC/PP/IA Processes

1. Community & parent **engagement**
 - Plan info dissemination strategies early
 - Establish ongoing consultation & feedback mechanisms
2. Improving **comprehension**
 - Sensitization meetings/households visits (timing & undue pressure!)
 - Two-way, child-centered language & approaches
3. **Ongoing IC**
 - Opportunities for free decision-making
 - Verbal/non-verbal cues

Sources: John et al., 2008; Okello et al., 2013; Vreeman et al., 2012

WITH children!

Assent Forms to Record Children's Decisions

- Media & conversation
 - Simple language, large print, diagrams & pictures
 - Multimedia & audiovisual approaches
 - Paper/text
 - Video
 - Animation
 - Verbal
- Two-way process

Sources: Dockett & Perry, 2011; Dolores & McCarthy, 2005; O'Lonegan & Forster-Harwood, 2011; Ruiz-Casares, 2014

Children and Young People's Hospital Project
Newsletter for Young People

Hi, my name is Veronica and I am inviting you to take part in a project. I want to find out what you think about things you were told about while in hospital, like what was happening to you and your illness. Did you understand what you were told? Did you get to have a say and did you feel you were listened to?


I have to do this project as part of my work for Trinity College where I study. I am asking you to join because you are a patient in hospital so you can tell me what it is like.

This project will take place at the hospital. I will visit the ward everyday when you are in hospital. Sometimes I just 'hang-out' and watch what is going on. Other times I chat to children and young people about what they think about what's going on? You can say what you think by talking to me or by doing other things such as writing and drawing.

You might feel tired at times; this is because you feel sick as well. So remember if you just want to be on your own to rest ask Veronica to STOP or TAKE A BREAK.

It is important that you know that this project may not help you when you are in hospital but what I learn from the project may help other children and young people in hospital in the future.

Veronica will only discuss her project with her supervisor in college but she will not tell her your name, this will be kept private.



It is completely up to you if you want to take part or not - YOU DECIDE!

You do not have to take part in this project. It is up to you to say YES or NO. If you say YES you can change your mind later and STOP AT ANY TIME.

Do you have any questions?

Ask as many questions as you like at anytime, now or later.



If you decide to say YES to take part in this project you will be asked to sign a consent form. You will get copy of this form to take home.

Researcher Contact Details:
 If you have more questions and want more information about this project phone Veronica – XX-XXXXXXX / XXX-XXXXXXX



Source: Lambert & Glacken, 2011

'Newsletter' for Children
Children and Young People's Hospital Project


Would you like to take part in a project?
My name is Veronica and I am doing a project about what children and young people think about things they are told when in hospital. I have to do this project as part of my work for Trinity College where I study. I am asking you to join because you are a patient in hospital so you can tell me what it is like.


What will you do in the project?
This project will take place at the hospital. I will visit the ward everyday when you are in hospital. I will just watch you sometimes and talk to you other times about what is happening in hospital. You can pick some things to do, like drawing a picture, writing a story or doing some worksheets. You can decide.


What things may bother you about the project?
You might feel tired at times; this is because you feel sick as well. So remember if you just want to be on your own to rest ask Veronica to STOP or TAKE A BREAK. You might feel sad if you remember things that you did not like, this is okay you can talk to me about these if you want to. I will try not to let this happen.




What's good about this project?
This project is good because you can have your say. It is important that you know that this project may not help you when you are in hospital but what I learn from the project may help other children in hospital in the future.




Who else will Veronica tell about what I say?
Veronica will only talk about her project with her supervisor in college (who is like a teacher in school). She will not tell her your name this will be kept secret. If something you say worries Veronica about your safety or about someone else's safety she might have to tell her supervisor. This is to keep all children safe. Veronica will talk about this with you first before she talks to someone else.




Do you want to take part or not? - YOU DECIDE!
You do not have to take part in this project. It is up to you to say YES or NO. No one will be mad or upset if you do not want to. If you say YES you can change your mind later and STOP AT ANY TIME.



Before deciding to help with this project?
Take time to think. Talk about this project with your Mam, Dad, Brothers and sisters before you say YES or No.



Do you have any questions?
Ask as many questions as you like at anytime, now or later.




If you decide to say YES to take part in this project you will be asked to sign an O.K form.

For More Information
More Questions
About this project
Phone Veronica - XX-XXXXXXX / XXX-XXXXXXX


Source: Lambert & Glacken, 2011

O.K - Assent Form for Children
Children and Young People's Hospital Project


I, _____ have been asked to be in this project. It is about children in hospital.
Veronica has explained it to me.




Veronica has told me this project is to learn about what children think of the things they are told about in hospital.




This project will take place at the hospital.
I know that Veronica will visit the ward everyday. I am happy for Veronica to watch me sometimes and talk to me sometimes about what is happening in hospital.



I can pick some things to do, like, draw a picture, write a story or do some worksheets. Veronica has explained these things to me. I can decide.



If I feel tired or sad, or just want to be on my own I can ask Veronica to STOP or TAKE A BREAK.




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I know this project may not help me but what they learn from the project may help other children in hospital.


I know I do not have to do this project.
IT'S UP TO ME!
No one will be mad at me if I do not want to, or if I decide to STOP AT ANY TIME.




I know I can ask Questions Now or Later.



I have been promised that anything Veronica learns about me will be kept as secret as possible.
Veronica has talked about this with me.



For More Information
More Questions
About this project
Phone Veronica - 01-8200073 / 087-2483877



THE END













I really want to help in this project

Child's Signature _____








Researcher's Signature _____

Date / Time _____

Source: Lambert & Glacken, 2011

 <p>Child assent form</p> <p>We would like to find out about your town. We would like to talk to you about the things you like to do in your town and what it is like to live in your town.</p> 	<p>We might ask you to have a conversation with us, take some photos, draw some pictures, make a model or tell us in some other way about your town.</p>  <p>We would like to record these activities.</p> 	<p>We have asked your parents if it is ok if we talk to you and they have said yes. Now we want to know if you would like to talk to us about what you like about your town?</p> <p>If you would like to talk to us please write your name just here.</p>  	<p>And for you can circle the face that tells us how you feel about talking to us.</p> 
<p>We will look at and listen back to what you tell us about your town so we can tell other people the types of things you would like to have in your town.</p>  <p>When we tell other people what you think about your town we won't use your real name.</p> 	<p>Would you like to choose another name for us to use?</p>  <p>You can tell us anything you like about your town, but if you tell us something that makes us worried about your safety we will tell someone who can help you.</p> 	<p>If once you have started to talk to us and you decide you no longer want to talk to us that is ok, you can stop, we won't mind.</p>  <p>If you have any questions or would like to talk about this, ask your Mum, Dad or teacher to phone us on 02 6051 9403 or email Sue sdockett@csu.edu.au</p>	<p>Thank you for your help</p> 

Source: Dockett, Perry & Kearney, 2013

 <p>Building a child friendly city: Consultations with children and young people</p> <p>Youth Information Sheet</p> <p>Charles Sturt University and Wodonga City Council are inviting children and young people in Wodonga to tell us about their city. We are committed to improving the quality of this city and we would like to talk to you about the things you like to do in your town and what it is like to live in Wodonga.</p> <p>If you agree to be involved in this project you will participate in one or a number of activities that will help us document how we might improve this city to make it better for you.</p> <p>There will be opportunities to be creative and to talk about whatever you think is important for us to know about what you think should happen in Wodonga.</p> <p>We want to hear what you have to say about your town and what it is like to live in Wodonga</p>  <p>We also want to know what you imagine would make Wodonga a better place to live</p>  <p>1</p>	<p>You can participate in this project in whatever way you wish. You may want to do one or all of the activities available. You may not wish to participate at all that is entirely up to you.</p>  <p>If you tell us something that makes us worry about your safety we will tell someone who can help you.</p>  <p>If you don't want to talk to us or work with us on this project at some time in the future you can stop participating at any time, we won't mind.</p> <p>Anything you say is confidential and won't be identified as coming from you. We will only identify you in our reports if you give us permission.</p>  <p>If you don't like the way we are doing something in this project you have the right to complain by phoning us or our supervisors.</p> <p>If you would like more information you can contact Professor Sue Dockett on (02) 6051 9403 or email her sdockett@csu.edu.au</p>  <p>2</p>
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Source: Dockett, Perry & Kearney, 2013

Building a child friendly city: Consultations with children and young people

Consent Form – Youth

Dear _____

We are seeking your assistance in conducting a research study entitled *Building a child friendly city: Consultations with children and young people* that is designed to involve children as decision makers, respecting their views and experiences as having a valuable contribution to make, when determining what constitutes a child friendly community. Detailed information concerning the project is provided in the attached information sheet.

As outlined on the information sheet, you may be involved in one or a number of the activities listed. If it is all with you we would like to record your contribution whether it be via audio tape or visual records of your work. Any information or personal details gathered in the course of this research about you are confidential and neither your name or any other identifying information will be used or published without your further consent.

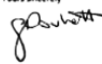
We welcome your participation in this research project. However, there is no obligation to be involved. Even if you choose to participate in this project it is still possible to withdraw from the project at any time. It is also possible to be involved for whatever parts of the project you choose. There are no negative consequences for you should you choose not to participate or if you can only participate in some parts of the project.

If you are willing to be involved, we would appreciate it if you could complete the attached consent form and return it to us in the enclosed reply paid envelope.

Your parents have also been given a consent form to complete and it is the combination of both your consent and their consent that will enable you to participate in the research project.

I can be contacted using the details listed below if you would like any further information.

Yours sincerely



Sue Dockett
Professor of Education
Murray School of Education
Charles Sturt University
Phone: 02-60519455
Fax: 02-60519424
Email: sdockett@csu.edu.au

NOTE: Charles Sturt University's Ethics in Human Research Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:

The Executive Officer
Ethics in Human Research Committee
Academic Secretariat
Charles Sturt University
Private Mail Bag 28
Bathurst NSW 2795

Tel: (02) 6336 4628
Fax: (02) 6336 4594

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.

Consent from Youth

I have read and understand the information about the study *Building a child friendly city: Consultations with children and young people* contained in the accompanying information sheet.

I have been able to clarify any questions I had about the project and my participation in it.

I understand that I am free to withdraw from the research at any time, and that if I do I will not be subjected to any penalty or discriminatory treatment.

I understand that any information or personal details gathered in the course of this research about me are confidential and that neither my name nor any other identifying information will be used or published.

Youth Consent

I, _____ (Youth's name) agree to be involved in any of the outlined activities as stated in the information sheet provided.

Name: _____

Signature: _____

Date: _____

Source: Dockett, Perry & Kearney, 2013

Visual Informed Consent (VIC) Forms



Sources: Ruiz-Casares & Thompson, 2014, in progress

Children's Dissent



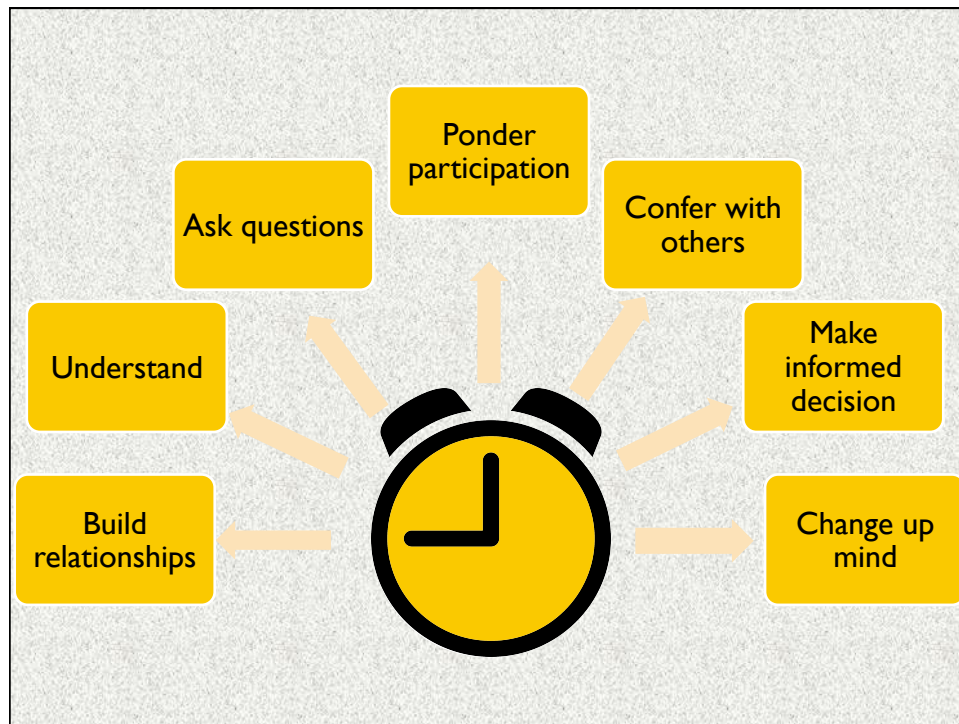
- Does not need to be justified
- Can be expressed at any time & way (non-/verbal)
- May pertain any level of involvement
- Is binding
 - even when it impacts on the evaluation!
- May be a gatekeeping strategy
- Children should be offered genuine choices about participation

Source: Dockett, Einarsdottir & Perry, 2012

Strategies to Enhance Voluntariness

- Saying 'pass'
- Holding up a 'yellow card'
- Holding up a 'green card' or a 'red card'
- Turning on/off recording device
- Opportunities to pause/stop the conversation
- Observe subtle signs of refusal/changes in children's behavior

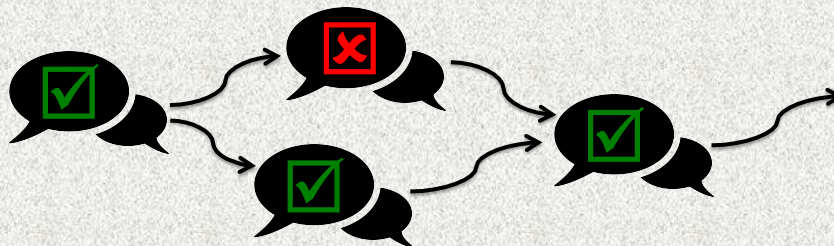
Source: Lambert & Glacken, 2011



Assent as Two-Way Process

- A:** Assess child's capacity/readiness to assent and engage with child to build rapport
- S:** Supply child with adequate and comprehensible verbal and written information
- S:** Search for signs of refusal (subtle or obvious) and ensure no pressure is applied
- E:** Evaluate evidence of the child's understanding through questions and feedback
- N:** Negotiate assent continuously
- T:** Time is allocated for the child to think about whether to participate, or not

Source: Lambert & Glacken, 2011, p. 7



Relationships + Conversation + Time + Context

Contact:

monica.ruizcasares@mcgill.ca