THEME : BIOETHICS

New bioethics club comes to campus

The Statesman, by Daniel Pariseau, March 8, 2020

The SBU Bioethics Society, a new club this semester at Stony Brook University, held its first-ever general body meeting on March 2 in the Frank Melville Jr. Memorial Library.

According to SB Engaged, the Bioethics Society allows students to explore a diverse range of subjects in bioethics. Students, regardless of whether they are familiar with bioethics, are encouraged to visit the club to learn about ethical issues faced by the scientific community.

“The Bioethics Society is a club that provides a safe space for students to talk about controversial topics in bioethics in a fun and engaging way,” Lamiya Jubaed, a sophomore biology major and the club’s president and founder, said. “It’s more of discussing the facts [and] really getting a feel of different opinions and perspectives.”

She added that Stony Brook University students from any major can join the Bioethics Society.

Jubaed, who transferred from Hunter College in the fall, said she “found it really interesting that all the physicians were talking about all these issues in the health care field that they were discovering once they became doctors.”

When she transferred to Stony Brook University, she discovered there was no bioethics club.

“[There are] so many people here trying to be pre-health, and it’s a great opportunity for everybody to have those resources, have exposure to that, and really learn more so that when they do get to their careers, they already have experience with this,” she said.

Bioethics, according to the Center for Practical Bioethics’ website, is the question of morality “in the context of modern medicine and healthcare.” Bioethics mixes together fields such as history and philosophy with other fields like health policy and medicine to explore questions about how to ethically handle issues in healthcare worldwide, what the goal is for life sciences — and even the meaning of life and death.

Stony Brook University lists several graduate courses in bioethics on their website such as HCB 511 Bioethics, Disability & Community, HCB 502 Landmark Cases in Bioethics and HCB 514 Global Bioethics.

Caroline Gallager, a freshman electrical engineering major and the club’s vice president, said she hopes to help members become better speakers and debaters.

“One thing that I’m going to be doing [as the Vice President] is teaching everybody argumentation and public speaking,” she said. “I think that it’s really important if you want to be an advocate for change that you actually know how to express your idea [and] engage in meaningful and thoughtful discussions with people who might disagree with you.”

Gallager also touched on the importance of discussing bioethical topics such as CRISPR and GMOs.

CRISPR, according to the Jackson Library's website, stands for "Clustered Regularly Interspaced Short Palindromic Repeats." A video on the website by the McGovern Institute explains that CRISPR is a form of genetic editing that utilizes bacteria to alter DNA. The Jackson Library states that one of the ethical concerns that comes with this technology is that it could be used to alter human embryos.

The Purdue University's College of Agriculture explains that GMO stands for "Genetically Modified Organism." As the name implies, GMOs are living organisms that were genetically changed in some way. A lot of people have raised questions about the ethics and impact of genetically modifying organisms, especially crops, out of concern about potential harm to human health, the environment and even the "unnaturalness" of playing with DNA.

The Bioethics Society meeting on March 2 focused on welcoming new and potential members to the club.

Students were encouraged to participate in a multitude of games, such as a trivia game where students answered a series of questions about the club's e-board and a debate game in which students briefly explained why they supported a certain topic. Students also voted on potential names for the club's mascot, a blue teddy bear knitted by Gallager.

Beia Fulgencio, a senior health science major, is a new member of the SBU Bioethics Society. She is studying to become a cardiologist and believes the club will provide her with new knowledge about the scientific world and ethics for her career.

"I took a professional ethics course … and I really wanted to continue it after the course," she said. "Now that I have finished the course, I feel like this is gonna be an interesting continuation of it."

Sophomore electrical engineering major, Brandon Banarsi, is considering joining the SBU Bioethics Society. He became interested in checking out the club after his friends suggested he look into it.

"The group looks fun, so maybe every day will be an enjoyable experience," Banarsi said. He hopes to learn more about bioethics at the next club meetings.

Bioethics Faces a Virginity Test

Scientific American, by Jacob Appel, March 2, 2020

Banning a surgical repair that suggests a woman has never had intercourse might seem like a no-brainer—but it's not

Two controversies related to women's virginity have recently generated controversy among physicians and medical ethicists. The first of these is a campaign in Great Britain to ban hymenorrhaphy (often referred to by the broader term hymenoplasty), the surgical repair of the hymen in an effort to convey the appearance of prior sexual abstinence. The second involves legislative efforts in California and New York to criminalize virginity testing. Both efforts are clearly well-intentioned, yet each raises complex ethical concerns.

Women's virginity has historically been valued in some religious and cultural traditions, and evidence of past sexual intercourse may render women in certain groups unmarriable. This remains true today in some Muslim communities. The issue drew international attention in 2008 when a French court in Lille annulled a marriage (a ruling later overturned) after the husband discovered that his wife had misled him into thinking she was a virgin. The absence of an intact hymen—a mucosal tissue the protects the vaginal opening—is falsely believed to be evidence of unchastity. In reality, a wide range of non-sexual activities in girlhood many lead to the rupture of the membrane, which is often asymptomatic and goes unnoticed. A British study found that the hymen may even remain intact after intercourse.

In an attempt to create the illusion of virginity, Muslim women in Europe and the United States may undergo hymenorrhaphy, a surgical procedure in which the hymen is reconstructed. The procedure began to draw significant public notice after the premiere of Davide Sordella's 2008 film Women's Hearts, which tells the story of a women who travels from Italy to Morocco for the procedure. Hymenorrhaphy is increasingly available in both the United States and Great Britain. It takes approximately 30 minutes to one hour and costs between $1,500 and $5,250.

The purpose of banning this procedure is to protect women from pursuing, often under duress, a medically unnecessary operation and enduring its concomitant risks including infection. This motive is certainly admirable. One might compare such a ban to the similar campaign to stamp out female genital cutting (FGC) or "female circumcision" and its criminalization in the West. Unlike FGC, however, many of the clients pursuing hymenorrhaphy are adults.

Yet banning hymenorrhaphy might have a significant downside. Unable to obtain the procedure, Muslim women may then face severe consequences from limited marital prospects to intrafamilial violence for failing to prove their virginity. Until the state can protect these women from such devastating consequences, which will likely require sustained educational efforts and a fundamental change in community values, women in these communities may be the best judges of whether or not to pursue the surgery. Nobody else can weigh as meaningfully the risks of the procedure against the risks of forgoing it. Rather than FCG, a better analogy might be made to the reporting by physicians of intimate partner violence (IPV), which many jurisdictions do not require and some do not even permit—recognizing that victims of IPV are the individuals who can best determine whether such reporting serves their own interests.

In the United States, activists are not challenging hymenorrhaphy, but rather targeting the

virginity tests that make it seem necessary. The effort gained considerable traction in response to a statement by a musician known as T.I. on the podcast Ladies Like Us, in which he said that he takes his 18-year-old daughter on “yearly trips to the gynecologist to check her hymen.” His claim produced widespread public backlash.

California Assemblywoman Lorena Gonzalez of San Diego has introduced legislation to prohibit hymen examinations by physicians; doing so would lead to potential disciplinary action by the state medical board. In New York State, Assemblywoman Michaelle Solages of Elmont has gone one step further; her bill would render such exams a felony. By targeting the tests, the goal is to render hymenorrhaphy both unnecessary and useless. If one cannot test for an intact hymen, having an intact hymen becomes irrelevant. Among those organizations supporting an outright ban are the World Health Organization and the United Nations Human Rights office.

Any effort to prohibit a potential medical intervention, no matter how pernicious or unnecessary, should be approached with considerable care. Entangling the state in the physician-patient relationship is not without its own consequences and may impose serious limits on the meaningful autonomy of patients. One would not be surprised if an underground market arises in professional virginity assessors with no formal clinical training who will fill the void if physicians are excluded from the practice. Alternatively, many families may simply take women abroad for evaluation, potentially exposing them to additional dangers.

Finally, there is an argument to be made that the state should trend very lightly when intervening in the deeply held cultural and religious practices of minority groups, lest one alienate these groups further from mainstream American society. All too short a road runs from proscribing virginity tests to banning certain forms of garb or headwear.

Yet the state does have a meaningful interest in preventing physicians from engaging in procedures that serve no clinical purpose. If virginity tests actually did assess virginity, conducting them would still be an affront to Western values—but the issue of whether to prohibit them by law might prove more challenging. However, virginity tests assess virginity no more effectively than divining rods detect ground water or Ouija boards sense departed spirits. They are pseudoscience. The American College of Obstetricians and Gynecologists stated in 2007 that the procedure does not have any medical indication. Needless to say, preventing the practice of pseudoscience is one of the key reasons the state regulates physicians.

Banning hymenorrhaphy and virginity testing offer two distinct approaches to addressing the same fundamental challenge: how to protect vulnerable women from a cultural practice that most Westerners, and many of these women themselves, view as oppressive. The difference is that the former lets the consequences fall squarely on the potential victims. In contrast, banning virginity tests tackles the problem in a manner least likely to jeopardize their welfare. While in an ideal world, no need would exist for such legislative action, embracing a ban on virginity exams is the best way for the medical community to pass the ethical test it now confronts.

Coronavirus: what happened to America's bioethics commission?

www.bioedge.org, by Michael Cook, March 14, 2020

Let's look at the worse-case scenario for the coronavirus epidemic in the United States. According to a report in the New York Times, experts from the US Centers for Disease Control and Prevention and universities around the world came up with some very grim figures:

Between 160 million and 214 million Americans could be infected
Between 200,000 and 1.7 million people could die
Between 2.4 million and 21 million Americans could require hospitalization – but the US has only about 925,000 staffed hospital beds
These catastrophic outcomes are highly unlikely. But a pandemic which might kill hundreds of thousands of people seems like a good time for President Trump to get on the phone to his bioethics commission and ask for advice.

Ooops, there isn't one. The Administration decided not to follow the lead of Presidents Bush and Obama.

This bothers Christine Mitchell, the executive director at the Center for Bioethics at Harvard Medical School. She made a few interesting observations in an interview published in the New Yorker.

Social constraints. If a person doesn't have health insurance and doesn't come to be tested or treated, and if they don't have sick-time coverage and can't leave work, so they teach at a school, or they work at a restaurant, or do events that have large numbers of people, these are all ways in which the spread of a virus like this has to be managed—and yet can't be managed effectively because of our social-welfare policies, not just our health-care resources…

Unprepared. I'm appalled. We didn't get ourselves ready. We've had outbreaks—sars in 2003, H1N1 in 2009, Ebola in 2013, Zika in 2016. We've known, and the general population in some ways has known. They even have movies like "Contagion" that did a great job of sharing publicly what this is like, although it is fictional, and that we were going to have these kinds of infectious diseases in a global community that we have to be prepared to handle. And we didn't get ourselves as ready, in most cases, as we should have. There have been all these cuts to the C.D.C. budget, and the person who was the Ebola czar no longer exists in the new Administration.

A bioethics commission. I don't know which ethicists are advising the current Administration. The Trump Administration decided not to have a National Bioethics Commission, so there isn't one in place. So I don't know who's doing that…

Allocation decisions. We are going to have to figure out how we choose who has what kinds of resources, whether it's the testing piece, or it's inpatient treatment, or it's the testing of the new vaccines when we, a year or more away, get to the point where we've got something suitable for human testing. And then, if we've got vaccines to use, as we ramp those up, on whom are they used? One of the most live issues in this kind of debate is using those limited numbers of vaccines in the early days for first responders and health-care providers in order to maximize the capacity of the health-care system to treat the people for whom we don't have enough vaccines yet. So it's those kinds of allocation and rationing decisions that I worry about and anticipate are going to get more intense.

Bioethics in Practice: Dietary Supplements — Helpful or Harmful?

The Commentator, by Baruch Lerman, March 1, 2020

As I was scrolling through Facebook one night, I came across a meme depicting a scene in which a woman in Whole Foods insisted that her items be entered by the numbers on the barcode, instead of by a scanner, since, as she said, “I don’t want lasers to touch things I am going to eat.” After laughing for a good 30 seconds, I started thinking about the larger trend of health food crazes and fad diets that run in the same vein as this story. Even if this story itself is not factual, it is similar enough to common experiences with health crazes that it is 100% believable.

What exactly are the bioethical implications of health crazes and fad diets? There are several: the first issue is the little to no regulation in the field of “health products” and the second is whether such health products actually work in execution. The second issue is much easier to address. Most experts agree that the modern health crazes and fad diets are bunk and, in fact, are often harmful. Proper nutrition — especially for a growing child — is essential, and when those needs are not met irreparable damage, and perhaps even death, can result.

An example of the effects of this lack of safety regulation can be seen from the Prohibition era in the United States. Jamaica Ginger, colloquially known as “jamaica ginger,” was a medicinal product that contains 80% alcohol by weight and was sold over the counter before Prohibition. During Prohibition, the Federal Government made this variety of ginger available by prescription only, but allowed stores to sell an over-the counter-version that had a much higher ginger to alcohol ratio. Due to the high ginger content, the federal government thought that it would be impossible to be used as a recreational alcohol product. Distributors of the ginger changed the recipe to make it more palatable by adding tricresyl phosphate (TCP). Due to the low level of federal regulation, they were able to get away with it. However, there was an unintended consequence — TCP was actually a slow-acting neurotoxin. Due to the low level of federal regulation, many Americans were paralyzed in their hands and feet.

Similar to Jamaican Ginger, many of today's health products, and “dietary supplements” are not approved by the Federal Drug Administration (FDA). The FDA’s informational website states, “Federal law does not require dietary supplements to be proven safe to FDA's satisfaction before they are marketed.” Additionally, the FDA states that, in general, the first opportunity to take action against a company that produces a harmful product is only “after the product enters the marketplace.” At this point, the product may have caused injury to a consumer. This is shocking! The laws surrounding dietary supplements — everything from protein powder to vitamin supplements — do not ensure that products are safe to consume prior to their distribution, leaving the general population at a huge risk. Additionally, the FDA reports of multiple cases where action has been taken by the FDA due to unsafe products being sold. These products had “to be recalled because of proven or potential harmful effects” only after they were sold on the market and potentially harming people.

Beyond the lack of regulation, there are other unaddressed risks. For instance, the FDA states, “Taking a combination of supplements, using these products together with medicine, or substituting them in place of prescribed medicines could lead to harmful, even life-threatening, results.” Additionally, some supplements can have unwanted effects before, during and after medical procedures. An example is “bleeding” that can be caused by supplements containing “ garlic, ginkgo biloba, ginseng, and Vitamin E.” Additionally,

supplements containing kava or valerian “can increase the effects of anesthetics and other medications during surgery.”

Health supplements can be helpful, as many of them provide needed nutrients to people who otherwise would not be able to get them. However, there is a need for much more oversight of the industry, or else a horror story like ginger jake may happen again. Producers should also be required to print clear labels and information on how different supplements react with common supplements and medications. This would hold the producers accountable and ensure that their products are safe. If supplements are truly working like medications to prevent and heal illnesses, then they should be regulated like drugs to ensure the safety of consumers.

Assisted suicide makes good economic sense, argue Scottish academics

www.bioedge.org, by Michael Cook, March 15, 2020

A new study in the journal Clinical Ethics claims that permitting assisted dying would substantially benefit both those seeking assisted suicide and the public.

Two Scottish academics, Dr David Shaw of the Universities of Basel and Maastricht, and Professor Alec Morton of the University of Strathclyde, posit three economic arguments: the cost to terminally-ill patients of a poor quality of life, the cost of care that could be better used elsewhere and potential benefits to organ donation (PDF here).

Dr Shaw, the lead author, said: “Some people might suggest that it is callous to consider assisted dying from the perspective of resource management; these are real people with real lives. This criticism is misplaced. Part of the motivation for our argument is precisely that these are real people with real lives who wish to avoid suffering.

The first argument is that it enables consenting patients to avoid negative ‘quality-adjusted life years’ (QALYS).

QALYs are a measurement of disease burden which encompasses the quality and quantity of life lived which is used by health professionals to determine the value of health outcomes.

Second, resources consumed by patients who are denied assisted dying could instead be used to provide additional QALYs for patients elsewhere who wish to continue living and improve their quality of life.

Third, organ donation may provide an additional source of QALYs in this context.

The authors argue that, together, the avoidance of negative QALYs and gain in positive QALYs suggests permitting assisted dying would substantially benefit both the small population that seeks assisted suicide and the larger general population.

They argue that denying assisted dying is a lose-lose situation for all patients.

In the paper the authors write:

“Quality-adjusted life years have been used for decades in healthcare allocation decision-making.

“By combining quality of life and mortality into one metric, they enable quantification of the medical gains and losses and relative financial costs of a vast diversity of treatments and interventions, in turn enabling these different treatments to be compared against each other and funding decisions to be made.

“Organ donation could also benefit because there are several reasons why donation after assisted dying is better from a clinical and economic perspective.

“First, if patients are denied assisted dying, organ function will gradually deteriorate until they die naturally, meaning that transplantation is less likely to be successful. Second, patients who choose assisted dying have to go through a lengthy process, and organ

donation can be easily integrated into that process, non-coercively, decreasing the risk that family members will attempt to overrule donation, which often occurs when a patient dies in a way that is not planned.

“The legal arrangements for assisted dying vary widely from country to country, and if the UK was to legalise assisted dying (presumably in the form of assisted suicide) the calculations here could be made more precise based on the specifics of the approach under consideration. Nevertheless, our paper shows in general that denying dying plausibly imposes great costs on both patients who wish to die and those who do not.

“However, our argument is not that legalisation of assisted dying should be primarily based on economic arguments; these are supplemental facts that should not be neglected. Legalising assisted dying in the UK is likely to yield a substantial increase in QALYs across the patient population as a whole.”

Dr Gordon Macdonald, of the lobby group Care Not Killing, which opposes assisted suicide, said: “This report is highly disturbing. It highlights the dangers of legalising euthanasia. Very quickly the argument moves from that of personal autonomy to doctors and nurses making value judgments about the quality of other people’s lives while seeking to save money and tackle so-called ‘bed blocking’ in health services.”

The Silent Crisis of Bioethics Illiteracy

Scientific American, by Jacob Appel, November 5, 2019

End-of-life decision-making is just one of the challenges that many Americans are likely to encounter but for which few adequately prepare

Many Americans will face some form of significant medical decision-making during their lifetimes, either for themselves or for their loved ones. Often, the choices they confront will raise challenging ethical questions: when to remove a relative from life support, whether to donate an organ to a family member, how to approach screening of an expected child in utero.

Unfortunately, most of us give little thought to these issues until they actually arise, and then we find ourselves woefully underprepared for the complex dilemmas we face. This need not be the case. However, change will only occur when bioethics is broadly incorporated into school curricula and when our nation's thought leaders begin to place emphasis on the importance of reflecting meaningfully in advance upon these issues.

Reasons for bioethics illiteracy are as numerous as the issues patients and family members are likely to confront. The steep decline of religious engagement and social capital starting in the 1960s has occurred simultaneously with rapid and transformative advances in medical technology, creating a vacuum in which Americans confront increasingly more difficult choices without the ability to rely upon traditional moral and communal guideposts.

More recently, the deep polarization of the political process has spilled over into the bioethics arena—first with abortion in the 1970s, and later into areas such as aid in dying, stem cell research and the allocation of health care resources. The consequences of this polarity were seen most notably in claims that Section 1233 of the Affordable Health Choices Act of 2009, which would have reimbursed physicians for advance directive counseling through Medicare, would lead to so-called "death panels," and in the media circus surrounding the case of Terri Schiavo.

School boards may fear that ideologues of various persuasions will respond negatively to bioethics education and so eschew taking the risk of teaching the subject. Yet the barriers to bioethics literacy may be even more fundamental: an aversion to addressing matters perceived to be painful or difficult or a fear of drowning in a sea of complex, technical information.

End-of-life decision-making offers one challenge that many Americans are likely to encounter and for which few adequately prepare. As of 2017, only 36.7 percent of Americans had completed any form of advance directive either indicating their medical wishes or appointing a health care decision-maker in the case that they were to become incapacitated. Far fewer, in my experience, have done so in a productive way: discussing their preferences with their proxy or relatives, documenting their directive in a manner that is accessible, etc.

On numerous occasions as a physician, I have called a patient's appointed health care decision maker and discovered that the patient had never informed the proxy of her role, let alone discussed his wishes. Studies have shown that a significant plurality of proxies do not know patients' preferences on such matters as basic as code status, and the number is likely lower for decision-makers who are not formal proxies, but merely family members

called upon for guidance. When I survey audiences, one of the leading places people store their advance directive forms is in their safe deposit boxes, to which they may not have access during a severe illness. Even a close colleague who taught bioethics with me at a major university refused to discuss or document his medical wishes in advance, dismissing my urging as “inviting bad news.”

The consequences cannot be overstated. For society, the costs are often economic: millions expended on “heroic” measures that patients never desired. For physicians, the emotional burden of providing futile or excessive care can be severe. And for relatives, already overwhelmed by the grave suffering of a loved one, rendering decisions in the ether of darkness can prove a genuine torment—sometimes even tearing families apart. Two sisters may disagree, for instance, on whether a patient would want artificial nutrition, leading to conflict that might have been prevented with an earlier discussion with their brother.

The tools to incorporate such issues into our education agenda are readily available. I designed a two-part secondary school bioethics curriculum for the New York Times’ Learning Network last year. An even more extensive curriculum for teens is available from New York University’s School of Medicine. Needless to say, such curricula cannot address all of the theoretical issues that might arise over a lifetime. Rather, they can provide flexible tools for recognizing and grappling with a wide range of potential scenarios.

Often merely recognizing such issues in advance is winning the greater part of the battle. Just as we teach calculus and poetry while recognizing that most students are unlikely to become mathematicians or bards, bioethics education offers a versatile skill set that can be applied to issues well outside the scientific arena. At present, bioethics is taught sporadically at various levels, but not with frequency, and even obtaining comprehensive data on its prevalence is daunting.

In addition, incorporating bioethics into school curricula at an early age can only improve our public discourse. Far too many of us see moral choices in black and white and believe that those who disagree with us on hot button topics in bioethics are genuinely evil. Without advancing particular causes or views, we can teach children the complexities and nuances of these issues—as well as an appreciation for the opinions of those with whom we disagree. Recognizing that our opponents are not our enemies, but rather well-intentioned people acting in good faith who start with different premises and thus arrive at different conclusions, is a necessary prerequisite for meaningful persuasion.

Our leaders might also emphasize the importance of bioethics literary. Regrettably, at present, our political and cultural icons rarely encourage such discourse. As of now, President Trump has gone over 1,000 days without appointing a bioethics commission, the longest delay in a generation. None of the other presidential candidates address the importance of these issues on a regular basis despite opportunities—including several with high profile healthcare scares—to do so. Yet a heart attack on the campaign trail or a controversy over genetic ancestry is precisely the moment to engage ordinary Americans in such discussions.

Significant strides have been made in the past generation in educating physicians and other health care professionals in ethics, although there is obviously still a long way to go. In contrast, almost no progress has been made in educating the general public. Yet as I often tell lay audiences, bioethicists are fun people to know: always armed with a salient anecdote or hypothetical to liven up a cocktail party or wedding.

The only place you do not want to meet us is in the hospital—and the soundest way to prevent that is to educate yourself on these subjects while you are healthy and to explore your values and goals with your loved ones. Widespread education on these issues, starting on the secondary school level, is the best way to ensure that this occurs.

Personal privacy matters during a pandemic — but less than it might at other times

www.theverge.com, by Nicole Westman, March 12, 2020

Public health weighs individual privacy against the common good

During a disease outbreak, one of the best tools at the disposal of public health officials is low-tech detective work. When a person is diagnosed with an illness like COVID-19, the disease caused by the novel coronavirus, public health experts figure out where they've recently been and track down everyone they've been in contact with.

"Sometimes it requires we know private information about a person who has been infected," says Lisa Lee, director of the division of Scholarly Integrity and Research Compliance at Virginia Tech and former executive director of the Obama administration's Presidential Bioethics Commission.

It also can mean that they have to share some of that information, including information about someone's health. Usually, people think about health privacy in terms of the relationship they have with their doctors and clinicians who have to keep the vast majority of information confidential — both legally and ethically. But the public health system is set up with different legal permissions and protections than a doctor's office, and by nature, it thinks about ethics and patient privacy differently.

"We think about it from the perspective of the mutual obligations we have towards each other and the need to protect well being," says Amy Fairchild, dean and professor in the college of public health at Ohio State University. "What you're doing is weighing the risks to the individual against the harm to the person's contacts and the rest of the population."

Legally, there are carve-outs in health privacy laws like HIPAA that allow public health officials to get information about a person's health without their consent. Individual privacy and the risks that can come from the disclosure of personal health information — like stigma — are still critical concerns for public health officials, Lee stresses. They aim to collect the minimum amount of information possible to achieve a public health goal. "The principle is to collect and use the least amount of data possible, because it reduces harm," she says. The information collected is also used only for public health activities.

The balance between protecting individual privacy and collecting information that is critical to the public good changes over the course of a disease's spread. The amount of data public health officials need to collect and disclose changes as well. Right now, the COVID-19 pandemic is accelerating, and there is still a lot doctors and scientists don't know about the disease. Collecting detailed health information is, therefore, more useful and important. That could change as the outbreak progresses, Lee says.

For example, as the virus starts to circulate in the community, it might not be as important to know exactly where a sick person has been. If the virus is everywhere already, that information won't have as much additional benefit to the community. "It depends a lot on the maturity of an epidemic," she says.

Digital tracking information is ubiquitous today, and that can make data collection easier. In Singapore, where there's extensive surveillance, publicly available data details where people with confirmed cases of COVID-19 are and have been. The Iranian government built an app for people to check their symptoms that also included a geo-tracking feature.

When deciding to use those types of tools, Lee says, the same public health principles should still apply.

“Should a public health official know where a person has gone, should that be public information — it’s not different. It’s a lot easier to do that now, but it doesn’t make it any more right or less right,” she says. “Tracking where people go and who they interact with is something public health officials have been doing for centuries. It’s just easier with digital information.”

In addition, just because personal information about a person and their health is important to a public health official, it doesn’t mean that information is important for the general public. It’s why, despite questioning from reporters, public health officials only gave out a limited amount of information on the people who had the first few cases of COVID-19 in the US.

During the polio epidemic in the US, health departments used to publish the names of people with confirmed cases of the illness in the newspapers — a practice that would be far out of bounds today. But that didn’t stop people in the US from trying to find out information about the few cases of Ebola in the country during the 2014 outbreak.

People didn’t need that information to protect themselves, though. “Having someone’s name doesn’t protect you,” Fairchild says. “That’s generally the principle of public health surveillance. There are emotional reasons that the public may want to know — but it doesn’t protect you, and shouldn’t change what you’re doing.”

Health officials worry about the stigmatization of individuals or communities affected by diseases, which is why they aim to disclose only necessary information to the public. Anti-Asian racism in the US and other countries around the world spiked with the outbreak because the novel coronavirus originated in China. People who were on cruise ships with positive cases reported fielding angry phone calls from strangers when they returned home, and residents of New Rochelle, New York, which is the first containment zone in the US, said that they’re worried about their hometown being forever associated with the virus.

“This kind of group-level harm is concerning,” Lee says. “That’s why we worry about group identity privacy, as well. I’m nervous and sad to see that starting to poke its head out.”

People can’t expect the same level of personal health privacy during public health emergencies involving infectious diseases as they can in other elements of their health. But the actions public health officials can take, like collecting information, aren’t designed to limit privacy, Fairchild says. “It’s to protect the broader population. The principle we embrace is the principle of reciprocity. We recognize that our liberty is limited, but we are doing that for others.”

Priest argues against treating children with puberty blockers

www.catholicleader.com, by Emile Ng, March 12,2020

CATHOLIC school authorities who become aware of children seeking to delay the onset of puberty with hormone blockers need to pursue a pastoral care strategy that was steeped in truth “not by political lobbying”, Perth bioethics director Fr Joseph Parkinson has said.

Fr Parkinson regularly offers advice to parents of children with gender dysphoria and incongruence, and is critical of the current clinical approach to caring for students experiencing distress with their sexuality.

“The current fashion to dress this up as gender incongruence and respond ac- cording to the rhetoric of the LGBTIQ++ lobby is unnecessary and possibly counter-productive in terms of providing sound, long-term support for all children in our care – not just for the few who claim gender incongruence status,” he said.

Fr Parkinson’s comments were in response to an ABC’s Four Corners report into the lives of four young Australians who have chosen to identify as non-binary, meaning they believe they are neither male nor female.

One of those young people was Olivia Purdie, an 11-year-old primary school student from Adelaide who is on puberty blockers to treat her gender dysphoria, which was diagnosed two years ago.

“I am non-binary, which means I have no gender. I am just me,” Olivia said on Four Corners.

At the recommendation of Olivia’s doctors, including a paediatric endocrinologist from the Women’s and Children’s Hospital of South Australia, she is receiving an injection of drugs designed to postpone puberty, including the development of breasts and menstruation.

This treatment was advised in order to alleviate Olivia’s distress with her birth gender and to provide an early intervention of a possible suicide.

“The benefit of a puberty blocker is that it gives a young person time to explore how they express their gender identity,” Olivia’s endocrinologist Dr Jemma Anderson told ABC’s Four Corners.

But Fr Parkinson said there were no credible studies showing the long-term effects of using hormone suppression treatments, including whether a child was less likely to suicide when given puberty blockers.

Studies that did claim such treatments lessened the likelihood of suicide were usually methodologically weak, he said.

“Medical practitioners, even those who advocate use of hormonal treatment, recognise that we have no real idea of the long-term effects it may have,” Fr Parkinson said.

“A few short-term trials have been published, but these also report mixed results: hormonal treatment often doesn’t alleviate gender dysphoria in the long run, nor reduce the effects of coinciding psychological pathologies.

“The claim is often made that hormonal treatment, by offering the child reassurance about the direction of their future body morphology, reduces the risk of suicide among gender incongruence children or, more popularly, if we don’t give the treatment the child is more likely to suicide.

“There are virtually no reliable data to support this claim.”

He said Catholic schools needed to await “future sound results” of longitudinal studies into the effects of medical treatments on children with gender anxieties, including the use of puberty blockers, and avoid the gender affirmation approaches of LGBTQI lobbyists.

This is consistent with Fr Parkinson’s 2014 research paper titled Pastoral Care for School Students who Experience Same-Sex Attraction, which concluded: “Schools must not blindly affirm a student’s felt same-sex orientation, but should provide excellent pastoral care designed to both support and challenge the student to ongoing growth.”

“Catholic education will be led forward over time by future sound results of reliable research into these questions – it would be at best premature, at worst irresponsible to allow our long-standing ethic of care for children to be derailed by what may well prove to be a temporary social phenomenon,” Fr Parkinson said.

“We must be led forward by the truth, not by political lobbying.”